

Faculty of Health Sciences

School of Nursing, Midwifery and Paramedicine

Nurses' perceptions of providing psychosexual care for women undergoing
gynaecological cancer treatment

Natalie Fleur Williams

Student number: 09818626

This thesis is presented for the degree of
Master of Philosophy (Nursing and Midwifery)

Curtin University

2018

DECLARATION

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made.

This thesis contains no material which has been accepted for an award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number SONM44-2014.

Signature:

A handwritten signature in dark ink, consisting of a series of loops and a long horizontal stroke.

Date: October 2018

ACKNOWLEDGEMENTS

I would like to take the opportunity to thank a number of people who provided me with the support to complete this thesis.

Firstly, my husband Craig who is a never-ending source of encouragement, love and support to me in all of my endeavours. I am truly blessed to be sharing this life with him and our three beautiful boys, Rhys, Asher and Ben.

To Prof. Yvonne Hauck who has been an incredible mentor and constant source of guidance to me for the past four years. Nothing has ever been too much trouble and I couldn't have asked for a more patient, knowledgeable and encouraging supervisor.

Thanks also to Anna Bosco for all her assistance in the early stages of the study, in particular conducting the interviews on my behalf.

Thank you to all the nurses who shared their thoughts and experiences during this investigation. May we all continue to work together to provide the best possible care for the women we serve as they travel through what is likely the most challenging and difficult time of their lives.

Finally, I would like to dedicate this work to my mum, Ann, who I was privileged and blessed to have known for the first 24 years of my life before she succumbed after her own cancer journey. Observing her kindness and caring to others during my youth is reflected in what I value most in my life and work.

"Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around."

-Leo Buscaglia

Publications, Presentations and Seminars

Publications
Williams, N., Hauck, Y., & Bosco, A. (2017). Nurses' perceptions of providing psychosexual care to women experiencing gynaecological cancer. <i>European Journal of Oncology Nursing</i> , 30, 35-42.
Conference presentations
CNSA Annual Congress, May 2016, Cairns – “Talking about sexuality: the perceptions of gynaecology cancer nurses”
Professional Development Seminars
<p>Women and Infant Research Foundation Rising Stars Event, September 2016 - “Talking about sexuality: the perceptions of gynaecology cancer nurses”</p> <p>Gynaecological Oncology Strategic Review and Research Meeting, King Edward Memorial Hospital, November 2016.</p> <p>King Edward Memorial Hospital “Psychosexual Care of Women with Gynaecological Cancer Study Day” – November 2012, November 2014, November 2015, November 2016, November 2017.</p>

ABSTRACT

Purpose

To gain insight into how Western Australian nurses conceptualise the provision of psychosexual care for women undergoing gynaecological cancer treatment.

Background

Gynaecological cancer can present significant challenges to a woman's sexuality. Women have expressed a desire for information, support and care relating to psychosexual issues and nurses are well-placed to provide this care. Despite this, the provision of psychosexual care is reportedly under-provided, or poorly addressed.

Methods

A qualitative descriptive design was chosen to facilitate insight into nurses' perspectives of their reality of providing care for women with gynaecological cancer. Seventeen nurses working at a tertiary women's hospital in Western Australia participated in one-on-one interviews and were asked to describe their perceptions and identify factors that facilitate or challenge psychosexual care provision. Interview transcripts were analysed using the systematic thematic analytical six step process outlined by Braun and Clarke. Data collection continued until data saturation was confirmed.

Results

Data analysis revealed five themes with nine corresponding subthemes that reflected the provision of psychosexual care: (1) Nurses use strategies to aid the conversation (subthemes: Supporting the woman, Facilitating engagement); (2) Women have unique psychosexual needs (subthemes: Diversity, Receptiveness); (3) Nurses are influenced by personal and professional experience and values (subthemes: Confidence, Values, Making assumptions); (4) Systems within the health service affect care (subthemes: Being supported

by the system, Working as a team); and (5) Society influences attitudes around sexuality. Nurses' views differed around whether these factors had a positive or negative impact on the conversation required to provide this care.

Discussion and Conclusions

Factors influencing nurses' provision of psychosexual care are multifaceted and differ amongst nurses. Concepts embedded within the themes are discussed including; the influence of rapport; making assumptions; and role clarification and expectations on nurses to discuss psychosexual issues. Strategies are recommended to improve service provision such as, including guidelines and documentation that incorporates assessment of psychosexual issues as standard care, encouraging shared responsibility of psychosexual care amongst the multidisciplinary team, and implementing education programs focussed on improving nurses' confidence and communication skills.

TABLE OF CONTENTS

DECLARATION.....	ii
ACKNOWLEDGEMENTS.....	iii
Publications, Presentations and Seminars.....	iv
ABSTRACT.....	v
LIST OF FIGURES.....	xi
LIST OF TABLES	xii
CHAPTER ONE: INTRODUCTION	1
Background.....	1
Gynaecological Cancer Care in Western Australia	3
Gynaecological Cancers: An Overview.....	3
Defining Sexuality	8
Significance and Purpose.....	10
Research Objectives	10
Overview of the Thesis	11
CHAPTER TWO: LITERATURE REVIEW	12
Introduction	12
Search Strategy	12
The Impact of Gynaecological Cancer on Sexuality.....	13
Women’s Desire for Psychosexual Care.....	19
Provision of Psychosexual Care.....	22
Nurses and the Under-provision of Psychosexual Care.....	28

Psychosexual Care Education Resources for Health Professionals	35
Summary.....	39
CHAPTER THREE: METHODS	40
Chapter Overview	40
Research Terminology.....	40
Paradigms in Research: Positivist and Naturalistic.....	41
Choosing a research paradigm.....	43
Choosing a qualitative design.....	44
The Author as a Methodological Instrument.....	51
Setting.....	52
Participants	53
Data Collection	54
Data Analysis.....	56
Trustworthiness	60
Ethical Considerations.....	62
Summary.....	62
CHAPTER FOUR: FINDINGS	64
Introduction	64
Participants Profile	64
Summary of Themes and Subthemes.....	66
Theme 1: Nurses use strategies to aid the conversation.....	69
Theme 2: Women have unique psychosexual needs	73

Theme 3: Nurses are influenced by personal and professional experience and values	76
Theme 4: Systems within the health service affect care	82
Theme 5: Society influences attitudes around sexuality	86
Conclusion.....	87
CHAPTER FIVE: DISCUSSION, RECOMMENDATIONS AND CONCLUSION	89
Introduction	89
Brief Overview of Findings	89
Comparison with Existing Literature	90
The influence of rapport	91
Making assumptions.....	97
Role clarification and expectations on nurses to provide psychosexual care.....	104
Application of findings.....	110
Summary of recommendations	110
Study Limitations.....	112
Conclusion.....	113
References	115
APPENDIX A	133
Demographic Information	133
APPENDIX B	134
Information Sheet.....	134
APPENDIX C.....	135

Interview guide.....	135
APPENDIX D	136
Consent Form	136

LIST OF FIGURES

Figure 1 Sample of coding during primary analysis of interview transcripts58

Figure 2 Sample of categories, their descriptions and accompanying quotes59

LIST OF TABLES

Table 1 A Stepwise Approach to Discussing Sexual Issues	24
Table 2 BETTER Model for sexuality communication	26
Table 3 Learning Outcomes of Psychosexual Care of Women affected by Gynaecological Cancers (PSGC) Resource	37
Table 4 Comparison of Quantitative and Qualitative Research Methods	42
Table 5 Common Qualitative Methods	45
Table 6 Main Interview Questions	55
Table 7 Participants' demographic data	65
Table 8 Summary of theme and subtheme descriptions.....	68

CHAPTER ONE: INTRODUCTION

This chapter will present an introduction to the topic of psychosexual care within the context of gynaecological cancer and justification as to why understanding the perceptions of nurses in providing this care was necessary. Firstly, background surrounding the study will be presented, the relevance of sexuality in relation to gynaecological cancer care, what is known about the practice of psychosexual care and where the current gaps in research lie. Next, the setting in which the study was conducted will be described providing the reader with the context of the Australian health care system within which the investigation occurred. Following on, the author will provide an overview of gynaecological cancer defining the four main types of cancer comprising this cancer group and describing the epidemiological relevance within the Australian environment. Definitions of sexuality are then presented to set the scene for how this term will be signified throughout the thesis. Finally, the significance, purpose, aims and an overview of the remainder of the thesis will be outlined to provide a synopsis of the forthcoming chapters.

Background

Sexuality is complex and affects individuals in a unique way. According to the World Health Organisation (WHO)(2006), it is a central aspect to being human and encompasses not only sexual function but a variety of dimensions which are core to a woman's sexual identity. In gynaecological cancer, the organs affected are those with which a woman typically identifies as central to her sense of being female (Wilmoth & Spinelli, 2000). Gynaecological cancer is known to have physical effects on sexual function, fertility and reproduction, hormonal changes, fatigue and bladder and bowel disturbances (Abbott-Anderson & Kwekkeboom, 2012; Gilbert, Ussher & Perz, 2011; Grimm et al., 2015; Hopkins et al., 2015; Lee et al., 2015; Wilmoth & Spinelli, 2000). If left unmanaged, these psychological and physical factors have the capacity to have a detrimental impact on the affected woman's quality of life.

There is acknowledgement that provision of information and clinical care related to sexuality concerns for women with gynaecological cancer is an essential component of quality care (Cancer Australia, 2016) and that nurses are well placed to provide this care (Ayaz, 2013; Booth, Beaver, Kitchener, O'Neill & Farrell, 2005; Chan, Button, Thomas, Gates & Yates, 2018; Cook, McIntyre, Recoche & Lee, 2017). However, it is known that psychosexual care is often under-provided, or poorly addressed by health professionals including nurses, (Ayaz, 2013; Ferreira, Gozzo, Panobianco, dos Santos & de Almeida, 2015; Gilbert, Perz & Ussher, 2016; Park, Norris & Bober, 2009; Saunamäki, Andersson & Engström, 2010; Sporn et al., 2015; Stead, Brown, Fallowfield & Selby, 2003) despite evidence that women wish to receive it (Bal, Yilmaz & Beji, 2013; Ekwall, Ternstedt & Sorbe, 2003; Hordern & Street, 2007a; Lara, de Andrade, Consolo & Romao, 2012; Rasmusson & Thome, 2008; Sporn et al., 2015; Stead et al., 2003; Vermeer, Bakker, Kenter, Stiggelbout & Ter Kuile, 2016; Wilmoth, Hatmaker Flanigan, LaLoggia & Nixon, 2011).

Investigations in the United States (Julien, Thom & Kline, 2010; Magnan, Reynolds & Galvin, 2005; Magnan & Reynolds, 2006), China (Zeng, Liu & Loke, 2012) and Taiwan (Tsai, 2004), have explored the reasons for this gap in psychosexual care. However, no studies relating to the provision of psychosexual care by nurses for women with gynaecological cancer have previously been conducted in Australia. Gaps in psychosexual health care knowledge were recognised by Cancer Australia (2010) who consequently developed and implemented a freely available online resource for health professionals "The Psychosexual Care of Women Affected by Gynaecological Cancers". Despite a comprehensive national implementation and educational strategy, no further evaluation of this resource was published. The effectiveness of this resource to influence clinical care and the psychosexual outcomes of women with gynaecological cancer is therefore still unknown.

Gynaecological Cancer Care in Western Australia

In Australia, individuals have the choice to access health care either within the public or private health system. Under the tertiary hospital public system patients can access care without out-of-pocket expenses. Alternatively, they can also choose to pay and access private care in a private hospital allowing them a choice of treating physician (Willis, Reynolds & Keleher, 2012).

It is estimated that over 6000 Australian women were diagnosed with gynaecological cancer in 2017 (Cancer Australia, 2017). In 2014, 503 women in Western Australia were diagnosed with a gynaecological cancer (Government of Western Australia, Department of Health, n.d.). The study outlined in this Masters thesis was conducted in a tertiary public health hospital setting, the primary referral centre for public gynaecological cancer care in Western Australia. This 254-bed hospital provides care to over 5000 gynaecological patients each year through a variety of services including: urology, general gynaecology, fertility, colposcopy, pelvic pain, sexual health, emergency centre and gynaecological oncology clinics (Government of Western Australia, n.d.). Gynaecological cancer care is provided under a holistic model whereby nurses play a key role in the multidisciplinary team throughout all stages from prevention, diagnosis, treatment, follow-up care, survivorship and palliative care (Government of Western Australia, Department of Health, 2009).

Gynaecological Cancers: An Overview

It is estimated that every day in Australia, at least 16 women are diagnosed with a gynaecological cancer (Cancer Australia, 2017). A combination of proven screening methods, quality diagnostic tools and ever-advancing treatment regimens means that 69% of these women will go on to survive their disease for at least five years (Cancer Australia, 2017). The impact of a cancer diagnosis is profound, affecting all facets of a person's life including but not limited to; physical effects of the disease and treatment, psychological impact of experiencing a life-threatening illness, economic impact of lost income and cost of treatment, and the social impact of how the experience has affected the

person and those around them (Cancer Australia, 2016). These effects are not limited to the treatment period but continue on throughout the survival or palliative period.

Gynaecological cancer is a collective term which represents a group of cancers originating in the female reproductive system. In Australia in 2017, gynaecological cancers accounted for almost 10% of all diagnosed cancers in females (Cancer Australia, 2017). The most commonly diagnosed types are ovarian, uterine and cervical cancer but also represented are the less common vulvar, vaginal, fallopian tube and placental cancers (Australian Institute of Health and Welfare [AIHW] & Cancer Australia, 2012). Each individual cancer type exhibits unique characteristics in its biological disease process, epidemiology, treatment and survival rates. The four most common gynaecological cancers are described in further detail below.

Uterine Cancer

Uterine cancer is the most common type of gynaecological cancer diagnosed in Australia at 44% of all gynaecological cancers (AIHW & Cancer Australia, 2012). The mean age of diagnosis for women with uterine cancer in 2008 was 64 years (AIHW & Cancer Australia, 2012). Cancers originating in the endometrium are the most common with *Adenocarcinoma* the most common pathological type (88%) and the less common *Sarcoma* and *Other and Unspecified* making up the remainder (AIHW & Cancer Australia, 2012).

Evidence which links the causation of the majority of endometrial cancer cases with unopposed oestrogen is resounding and high levels of adipose tissue seen in obesity is a significant cause of this oestrogen production (Ali, 2014).

Therefore, when examining the international incidence of endometrial cancer, it is not surprising that in developed nations like Australia and those in North America and Europe where the incidence of obesity is substantial, the rates of diagnosis are significantly higher than those of less developed nations (AIHW & Cancer Australia, 2012).

Endometrial cancer is associated with signs such as abnormal vaginal bleeding, which can warrant investigation by the woman and often results in an early-stage diagnosis. This characteristic is reflected in the high 5-year relative survival rates for *Uterine Adenocarcinoma* reported as 86% for 2006-2010 data (AIHW & Cancer Australia, 2012). Comparisons of international cancer statistics are challenging (AIHW & Cancer Australia, 2012), however it is suggested that Australian rates of survival from uterine cancer are amongst the highest in the world. Based on 2008 data, Australia boasts a mortality-to-incidence ratio (MIR) of 0.1, indicating there were 10 deaths from endometrial cancer for every 100 newly diagnosed cases that year. The lowest survival figures for uterine cancer were seen in South-Central Asia with a MIR of 1.0 (AIHW & Cancer Australia, 2012). The treatment course for endometrial cancer is determined by the level of disease progression at diagnosis. In most cases, it involves surgical removal of the uterus and a course of external beam radiotherapy (Jeppesen, Mogensen, Dehn & Jensen, 2015).

Ovarian Cancer

Ovarian cancer diagnoses were estimated to have made up 26% of gynaecological cancers diagnosed in Australia in 2015 (Cancer Australia, 2016). The mean age of diagnosis was similar to uterine cancer at 63 years and the most common type was *Carcinoma*, commonly known as epithelial tumours, making up 85% of diagnosed cases (AIHW & Cancer Australia, 2012).

There is much still to be learned about the disease process and causation of ovarian cancer. National data on the stage at diagnosis is not available in Australia but it is known that survival rates for cases detected in the early stages are higher than diagnosis at a later stage (AIHW & Cancer Australia, 2012). This may be due to the signs and symptoms of epithelial ovarian cancer often being nonspecific and attributable to other causes (AIHW & Cancer Australia, 2012). Diagnosis therefore most often occurs once the disease has become more advanced and this is reflected in poorer 5-year survival rates (42%) when compared with those of uterine cancer (86%) (AIHW & Cancer

Australia, 2012). On the other hand, the less common germ-cell tumour ovarian cancer, which makes up 3% of diagnosed cases, boasts a 95% relative survival rate which is representative of its different pathology and disease process. The treatment course depends on the stage of disease progression but most often involves a combination of surgery, chemotherapy and radiation treatment (AIHW & Cancer Australia, 2012).

Cervical Cancer

The incidence rates of cervical cancer in Australia are amongst the lowest in the world (4.9 per 100,000) when compared with international figures and this can be linked to an understanding of the disease process (AIHW & Cancer Australia, 2012). Infection with Human Papillomavirus (HPV) is the causative factor for 99% of cervical cancers (Australian Government National Cervical Screening Program, n.d.) as well as other anogenital cancers including those of the vulva and vagina (Cancer Council Australia Cervical Cancer Screening Guidelines Working Party, 2016). HPV is a common virus transmitted during sexual activity and is usually cleared by the body's immune system. Persistent infection with oncogenic types of HPV may cause cervical cellular changes known as squamous intraepithelial lesions which can then develop into cervical cancer (Cancer Council Australia Cervical Cancer Screening Guidelines Working Party, 2016).

The rates of cervical cancer in Australia have significantly decreased since the introduction of a National Cervical Cancer Screening Program introduced in 1990 after it was discovered that cervical cellular changes could be detected by a procedure known as the Papanicolaou (Pap) smear. Incidence rates of cervical cancer in Australia almost halved from 13.3 per 100,000 women in 1991, to 6.8 per 100,000 women in 2015 (AIHW & Cancer Australia, 2012). Detection of lesions exhibited in the cervix before invasive carcinoma takes hold meant that diagnosis and treatment can essentially prevent the progression to cancer (Cancer Council Australia Cervical Cancer Screening Guidelines Working Party, 2016).

Since the discovery of HPV, a vaccine has been developed and a national vaccination program was introduced in 2007 to protect vaccinated persons from infection with HPV types associated with 70 -80% of cervical cancer cases (Cancer Council Australia Cervical Cancer Screening Guidelines Working Party, 2016). This program was extended to males in 2013, and in 2018, a newly updated vaccine will help to protect females from nine HPV types that are associated with 90% of cervical cancers in Australia (Australian Government Department of Health, 2018).

Due to the understanding behind the causative factor of the majority of cervical cancers, the National Cervical Cancer Screening Program has since been renewed and in 2017, the previous scheme of women attending bi-annual Pap smears, has been replaced with a 5-yearly cervical screening test that detects infection with HPV (Cancer Council Australia Cervical Cancer Screening Guidelines Working Party, 2016).

It is expected that due to the introduction of these preventative strategies, cervical cancer rates will continue to decline over the coming years. For now though, cervical cancer was still diagnosed in 898 women in 2014, with an average age at diagnosis of 50 years (AIHW, 2017). The 5-year relative survival was 72% for 2006-2010 data but as with all cancers, survival rates differ depending on stage at diagnosis and histological type (AIHW & Cancer Australia, 2012). Treatment is usually a combination of surgery and both internally and externally delivered radiation therapy.

Vulvar Cancer

Vulvar cancer affects only a very small percentage of women, 6% of all gynaecological cancers, with the average age of diagnosis being higher than other gynaecological cancers, at 67 years (AIHW & Cancer Australia, 2012). Due to its lower incidence, cancer of the vulva does not attract as much research attention as the other gynaecological cancers, however its association with HPV infection means that rates are expected to decrease over the coming years as with cervical cancer (Cancer Council Australia Cervical Cancer Screening

Guidelines Working Party, 2016). Estimated survival rates for cancer of the vulva in the period 2006-2010 were 87% at 1 year, 71% at 5 years and 61% at 10 years post diagnosis (AIHW & Cancer Australia, 2012).

Treatment is usually restricted to surgical removal of the tumour without the need for chemotherapy or radiation, however the anatomical nature of the disease means that this surgery can cause significant physical and psychological changes for the woman. The extent of the surgery is based on the depth of tissue invasion and for more advanced disease, a radical vulvectomy procedure is not uncommon. This surgery involves the removal of all the external tissue of the vulva, including the fatty tissue around the perineum, and is usually accompanied by the removal of lymph nodes in the groin on both sides (Robertson, 2005). As a result, it is not uncommon for women to experience major side effects including wound breakdown (25-50% of cases), lower leg lymphoedema, micturition difficulties and discomfort sitting for extended periods of time (Jefferies & Clifford, 2011). Five-year survival rates for early-stage squamous cell carcinomas of the vulva treated with these types of surgeries are reported as between 93-98% (DeSimone et al., 2007).

Defining Sexuality

The concept of sexuality is multidimensional and therefore not easily defined. In the same way the term 'health' holds different meanings and values for every individual, 'sexuality' is a concept influenced by a wide variety of factors, experiences, values and beliefs. In 2006, the World Health Organisation (WHO) published a report, "Defining sexual health" in which the term sexuality was described using a working definition. The WHO definition is now referenced widely amongst the literature. According to WHO:

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships.

While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors. (WHO, 2006, p.5)

This holistic definition encompasses the multifactorial dimensions that influence each individual's concept of sexuality.

Other literature have embraced this holistic concept through their own definitions of sexuality. Wilmoth and Spinelli (2000) describe sexuality as "more than the ability to have sexual intercourse" (p. 413), and that for women, sexuality includes "feelings about their body appearance, their femininity, their ability to bear children, and their ability to function sexually. Sexuality is an integral aspect of a woman's personality, with emotional, intellectual and sociocultural components" (p. 413).

Mick (2007) suggests that in order to better understand the concept of sexuality, nurses who care for patients with cancer should consider not only the functional aspects of sex in their assessment, but also how the patients' concerns about sexuality affect their quality of life. These may include issues such as body image, feelings of femininity (or masculinity), the patient's roles and responsibilities in the family and relationship concerns. By considering a sexuality assessment from the perspective of how a patient's quality of life is affected, they acknowledge the disruption that cancer can have on life and relationships as well as affecting feelings of self-worth and intimacy (Mick, 2007).

In the literature review by Cleary and Hegarty (2011), it was suggested that despite the existence of holistic definitions, these are not always used to guide cancer and sexuality related research. They describe sexuality as "an ambiguous concept which is used interchangeably with various other terms such as sexual health, sexual problems, sexual functioning and sexual

dysfunction” (Cleary & Hegarty, 2001, p. 38), thus recognising the inconsistency that exists around the definition.

When reviewing literature around sexuality and gynaecological cancer this focus on physical and biological sexual functioning was supported. The focus of many international studies, commentary papers and reviews was on physical and biological sexual functioning (Anderson, 2013; Brotto et al., 2008; Falk & Dizon, 2013; Flynn, Kew & Kisely, 2009; Hopkins et al., 2015; Iavazzo et al., 2015).

Significance and Purpose

Sexuality is a unique and individual construct influenced by a wide variety of factors including the social cultural context within which people live. It is suggested that the study of psychosexual concepts should be within a patient’s unique sociocultural environment and the results of studies from other sociocultural contexts may not translate internationally (Lee et al., 2015).

In order to address the gap in understanding factors influencing nurses’ provision of psychosexual care in an Australian context, this study aimed to gain insight into how Western Australian nurses conceptualise the provision of psychosexual care for women undergoing gynaecological cancer treatment.

Research Objectives

In order to achieve this aim, the following objectives were identified:

1. Explore how nurses discuss psychosexual care with women undergoing treatment for gynaecological cancer.
2. Identify factors that facilitate nurses’ ability to ask questions about psychosexual care.
3. Identify factors that challenge nurses’ ability to ask questions about psychosexual care.
4. Examine the perceptions of nurses around the provision of psychosexual care for women undergoing treatment for gynaecological cancer.

Overview of the Thesis

In Chapter Two, a review of the literature examining provision of psychosexual care for women with gynaecological cancer is outlined. This review includes an understanding of the impact of gynaecological cancer on women's sexuality, evidence surrounding women's desire to be provided with psychosexual care during their cancer journey, what psychosexual care provision entails and how it may be delivered, the role of the nurse and evidence pertaining to the under-provision of such care and finally, what is known about the education resources available to health care professionals on the topic of psychosexual care. Chapter Three rationalises the research design chosen for this investigation and describes the research process employed including a description of the participants, setting, recruitment methods, data collection and analytical procedures used along with ethical considerations. Chapter Four outlines the findings revealed through thematic analysis of the data collected and provides participant quotes to support the themes and subthemes presented. Chapter Five examines and discusses the findings of the investigation within the context of what is currently known, considers the limitations of the study, and provides recommendations for clinical practice, education and future research.

CHAPTER TWO: LITERATURE REVIEW

Introduction

In this literature review, a range of concepts related to the provision of psychosexual care for women with gynaecological cancer will be discussed. Firstly, a description of the search strategy employed for this literature review will be outlined. Secondly, the extent to which women's sexuality is impacted by the diagnosis and treatment of gynaecological cancer will be examined. Next, the author will discuss the concept of psychosexual care, what it is, who should be providing it, how it may be provided and some of the challenges that have been revealed in existing literature. Evidence will then be provided around the desire from women with gynaecological cancer to receive psychosexual care. The focus will then turn to health professionals and the reasons for the current under-provision of psychosexual care in practice. Finally, psychosexual care educational resources for health professionals will be discussed. Review of this evidence will contribute to the understanding of what is currently known around the topic and highlight the gap in knowledge being addressed in this research study around the issues that affect nurses' provision of psychosexual care for women with gynaecological cancer in the Australian context.

Search Strategy

A systematic search strategy was adopted to ensure a comprehensive and breadth of literature was reviewed around the topic of the practice and perspectives of health professionals on the provision of psychosexual care. Between December 2014 and April 2015, five major databases were explored and as a result over 100 relevant articles were discovered, with citations and articles downloaded and stored in the EndNote X7 referencing software program. PubMed was used as a primary source and then CINAHL, PsychInfo, Science Direct and Medline were searched using the same keywords revealing a small number of additional articles. Keywords used for initial searches included a combination of "psychosexual care", "gynaecological cancer", "nurses", "sexuality" and "communication". As relevant articles were discovered, the

search was expanded using combinations of further keywords including “women”, “assessment”, “cancer nursing”, and “quality of life”.

As a result of this initial search, six relevant reviews were discovered (Abbott-Anderson & Kwekkeboom, 2012; Ayaz, 2013; Gamel, Hengeveld & Davis, 2000; Gilbert, Ussher & Perz, 2011; Hordern, 2008; Kotronoulas, Papadopoulou & Patiraki, 2009). The reference lists of these reviews were systematically examined for further literature which was then appraised and downloaded if deemed relevant. Following the initial search, databases were periodically reviewed every few months to check for the publication of new relevant articles.

The Impact of Gynaecological Cancer on Sexuality

Wilmoth and Spinelli (2000) suggest that a diagnosis of gynaecological cancer can have a profound impact on a woman’s sexuality due to the nature of the organs it affects and their association with the female identity. The level of the effect varies greatly amongst women. The nature of the changes experienced are wide ranging and some women experience a greater degree of change than others (Abbott-Anderson & Kwekkeboom, 2012).

A systematic review of 37 international studies conducted by Abbott-Anderson and Kwekkeboom (2012) reported the sexual concerns of gynaecological cancer survivors covering the physical, psychological and social domains. The results confirmed that many of the physical concerns were related to dyspareunia, defined as pain associated with sexual activity. These included decreased sexual activity and satisfaction, difficulties with arousal and orgasm, and vaginal issues. Other physical concerns included menopausal symptoms, post-coital bleeding, fatigue and continence issues. Psychological concerns related to decreased interest or enjoyment of sexual activity, poor body image and fears. A third domain relating to social concerns highlighted the significant effect gynaecological cancer can have on relationships. Communication difficulties, perceived changes around interest in sexual activity and maintaining previous roles and expectations were all identified.

A Turkish cross-sectional study by Reis, Beji and Coskun (2010) suggests a fourth element by which quality of life for women with gynaecological cancer is affected, namely, spirituality. A mixed methods approach was adopted with quantitative data collected from 100 gynaecological cancer survivors using The Quality of Life-Cancer Survivors Instrument. Semi-structured in-depth interviews were also carried out with 30 of these participants focusing on their sexual life. Of these survivors, strong religious or moral activity was found to be protective of well-being. However, this was adversely affected by persistent negative thoughts about the disease and uncertainty about the future which challenged their spiritual being.

The extent to which women's sexuality is affected by gynaecological cancer is inconsistent amongst international literature (Gilbert, Ussher & Perz, 2011) with investigations citing a range of levels from no effect at all, through to all women being significantly affected.

Limited psychosexual impact on gynaecological cancer patients

The following four studies described below, reported low numbers of women affected by psychosexual issues related to their cancer experience.

A Korean cross-sectional study compared quality of life and sexual functioning between 103 sexually active ovarian cancer survivors and 200 healthy women (Kim et al., 2015). Almost all of the sexuality indicators investigated, including desire, arousal, lubrication, orgasm, satisfaction, and pain in terms of interest in sex, sexual activity and enjoyment, were described as similar between the two groups. The only indicator with borderline statistical significance between the two groups was vaginal dryness with the ovarian cancer survivors experiencing this more often than the healthy women. The eligibility criteria required participants to identify as having participated in sexual activity within the previous three months however no definition for the term 'sexual activity' was provided. As such, generalisability of these results to the complete ovarian cancer survivor population may be limited.

In Australia, Juraskova, Butow, Bonner, Robertson and Sharpe (2013) compared the sexual outcomes for 55 women treated for early-stage cervical and endometrial cancer, with 60 benign gynaecological patients and 52 pre-invasive cancer patients. Despite physical changes, there were no significant differences to the objective, subjective and overall measures of sexual function between the three groups at six months post-treatment. The authors of this multi-centre controlled study concluded that treatment for early-stage cervical and endometrial cancer has no impact on sexual adjustment.

Barlow, Hacker, Hussain and Parmenter (2014) used a qualitative approach to investigate the experiences of ten Australian women who had been conservatively treated for an early-stage vulvar cancer. While the women described a variety of changes and challenges, they reported little to no long-term disruption to their sexuality and body image as a result of their treatment. The transferability of the results of this study to other women diagnosed with gynaecological cancer or indeed those with vulvar cancer, may be limited by the small sample size and specific context of the cancer experience.

The Australian qualitative study by Barlow et al. (2014) supported earlier work from The Netherlands by Weijmar Schultz, van de Wiel, Bouma, Janssens and Littlewood (1990). Ten Dutch couples participated in a longitudinal study investigating sexual functioning before, during and after treatment for vulvar cancer. Measures including sexual behaviour, sexual motivation, sexual (dis)satisfaction and the sexual response were assessed using self-reported questionnaires. In these cases, the women had undergone extensive surgery, including radical or partial vulvectomy, bilateral lymph node dissection and for two women, removal of the clitoris. Despite the physical damage and poor perception of genital symptoms of sexual arousal, women's satisfaction with sexual interaction post-treatment was not found to be different from their pre-treatment satisfaction. The authors suggest that other variables such as psychological and social factors have more influence on satisfaction levels than physical variables. The small sample size was acknowledged by the authors, however the results were considered important due to the originality of the

study at the time. Given the rarity of vulvar cancer, the population from which study participants could be recruited would have been limited.

Moderate psychosexual impact on gynaecological cancer patients

A further six international studies investigating the impact of gynaecological cancer on sexuality reported mixed results with some women being affected and others unaffected.

In Germany, Grimm et al. (2015) conducted a multicentre cross-sectional study comparing the quality of life and sexual functioning scores of 77 women who had completed treatment for cervical, endometrial or vulvar cancer, with 60 healthy women. Of those women treated for gynaecological cancer, 41.3% (n=31) were sexually active compared with 78% (n=46) of the healthy women. The most commonly reported reason for sexual inactivity of the women with gynaecological cancer (42.9% or n=18/42) was the presence of a physical problem. Sexually active women treated for gynaecological cancer reported similar sexual functioning scores to healthy women on measures including habit, pleasure, discomfort and orgasm. So, while women who remained sexually active after treatment had sexual function comparable with healthy women, a high number of women were sexually inactive due to persistent functional problems.

Sekse, Hufthammer and Vika (2016) conducted a descriptive cross-sectional study to investigate the sexual satisfaction of 78 sexually active women who had been treated for a gynaecological cancer in Norway. Just over half of these women (54% or n=38/71) reported being either unsatisfied or a little satisfied with the sexual activity. For symptoms experienced during sexual activity, authors provided results in percentages only. Half of the women reported vaginal dryness (70% for ovarian, 50% for uterine, 33% for cervical and 0% for vulvar cancer) and 41% said they experienced pain or discomfort with penetration.

In the United Kingdom (UK), ovarian cancer survivors were invited to participate in a sexual activity survey using a paper-based questionnaire or an online format (Hopkins et al., 2015). For the 102 participants, results are conveyed in percentages with 63% reporting their ovarian cancer diagnosis had negatively changed their sex life. Of the 46% of women who identified as sexually active, 77% reported pain or discomfort during intercourse and 87% reported vaginal dryness.

In Canada, the supportive care needs of women who had completed treatment for gynaecological cancer were investigated using a cross-sectional study (McCallum et al., 2014). Of the 113 women surveyed, 36% (n=41) reported a level of need for help with reported “changes in the ability to have sex”, 36% (n=41) reported “changes in sexual feelings” and 29% (n=33) reported “changes in sexual relations”.

In the United States, a qualitative study using content analysis techniques investigated the experiences of 13 ovarian cancer patients and their changes in sexuality since diagnosis (Wilmoth et al., 2011). Of the 13 women, eight (62%) indicated their cancer had a detrimental impact on their sexuality. The women described their negative experience using wording such as “no longer whole”, “no one wants to touch you”, and “you lose your hair, you put on 20 some pounds and you don’t feel very sexual; so it has been greatly affected”. In this study, the women described sexuality in broad, holistic terms and did not focus solely on sexual activity.

In Ireland, a descriptive, correlational study of 106 women with a range of gynaecological cancers (cervical, ovarian, endometrial and vulvar) adopted a holistic framework by measuring not only sexual functioning but also sexual esteem, and sexual self-concept (Cleary, Hegarty & McCarthy, 2011). A range of variables were measured and amongst these, the effect of the cancer on sexuality was mixed. In relation to sexual functioning measured using the Arizona Sexual Experience Scale, the results indicated participants experienced poor functioning generally with 60% (n=44) reporting arousal difficulties, 64%

(n=47) reported lack of lubrication and 58% (n=43) reported difficulty or no ability to reach orgasm. The three scales used to measure sexual self-concept (Body Image Scale, Sexual Esteem Scale and Sexual Self-Schema Scale) revealed that overall, participants reported relatively positive body image with mean scores calculated as above average. However, in relation specifically to femininity, 51% (n=54) of women were affected as a result of their cancer diagnosis. Again, half (50%, n=52) indicated either moderately to extremely negative change when asked to rate the change in their sexual self-concept from pre-cancer diagnosis to after diagnosis, using a five-point Likert scale. Of the participants in a sexual relationship, 73% (n=55) indicated the frequency of intercourse had decreased since their diagnosis, however 27% (n=20) said their desire to be intimate in other ways had increased.

High psychosexual impact on gynaecological cancer patients

In contrast, a study conducted in Brazil, suggested that most or all women report psychosexual issues as a result of their cancer (Lara et al., 2012). In this cross-sectional descriptive study, the sample size of 30 women was gathered over a two-year period and included women who had undergone a radical hysterectomy as part of their treatment. Depending on their diagnosis, half (n=15) had also received chemotherapy and/or radiotherapy. At an appointment with a gynaecologist specialising in sex therapy, the women were asked to report their level of satisfaction with sexual activity both prior to and post treatment, using a four-point response scale (very unsatisfied to very satisfied). All women reported significantly worse outcomes in post-treatment satisfaction compared with pre-treatment scores ($p < 0.01$). Asking women to retrospectively rate their satisfaction level prior to treatment may have some limitations due to recall bias. Women were not asked prior to the treatment but were asked to rate their satisfaction at the same time as post-treatment levels. It is interesting to note that when asked if they had talked to their oncologist about their sex life, all women reported feeling ashamed to have the conversation and said they had not discussed it.

Contrasting evidence in the 11 publications cited above illustrates the unique nature of the gynaecological cancer experience. As gynaecological cancer is a term that encompasses not one, but rather a group of cancers affecting the female reproductive organs including ovary, uterus, cervix, and vulva; some of the inconsistencies in the results may be explained by examining the type of cancer being investigated, the stage of disease at diagnosis and the extent and type of treatment experienced by the woman. Other contributing factors may include the study's methodology and the societal context in which the study was conducted. However, the contrasting evidence may also be attributed to how the term sexuality is defined, with some studies focussing specifically on sexual functioning and others adopting a more holistic approach. The breadth of concerns and the diversity of who is affected demonstrate that the type and significance of psychosexual effects differs between women. As such, it is essential that treating health care professionals assess and provide individualised care based on the woman's own unique circumstances and priorities.

Women's Desire for Psychosexual Care

Psychosexual care is a term often used synonymously with phrases such as 'psychosexual information provision', 'sexuality assessment' and 'psychosexual counselling' (Ayaz, 2013; Fitch, Beaudoin & Johnson, 2013; Stead et al., 2003). For the purpose of this thesis, the author defines psychosexual care as the assessment and provision of information, advice and treatment around any issue that psychologically, physically or socially impacts the affected woman's body image or sexual function. This includes, but is not limited to, sexual intercourse. Other matters include those with the potential to disrupt sexual self-concept such as body image, femininity, roles and relationships and fertility (Kotronoulas et al., 2009; Magnan & Reynolds, 2006; Southard & Keller, 2009; Woods, 1987). International literature described below demonstrates that women have expressed a desire for health professionals to provide information, support and care relating to psychosexual issues.

As part of an Australian qualitative three-stage reflexive inquiry, 50 patients diagnosed with a range of cancer types were interviewed to explore their experiences of communication about sexuality with health professionals (Hordern & Street, 2007a). “Unmet needs” was reported as one of two major themes and patients indicated they wanted information on support and practical strategies for living with the sexual changes after cancer treatment, even if the cancer type did not directly affect fertility or sexual performance.

In Sweden, 11 women who had completed their treatment for gynaecological cancer were interviewed to explore their wishes and need for knowledge concerning sexuality and relationships (Rasmusson & Thome, 2008).

Interviews were analysed using a qualitative technique described as latent content analysis. Two common themes shared by women revealed they had an “absence of knowledge about the body” and desired a “conversation with sexual relevance”. They articulated that they wanted their partners to also be involved in the conversation.

More recently in The Netherlands, Vermeer et al. (2016) interviewed 30 cervical cancer survivors and 12 of their partners about their experience with sexual dysfunction and psychosexual support. A qualitative deductive framework approach was used to analyse interview data. In relation to the findings around experiences with information and care provision, women and their partners revealed wanting information about the sexual consequences of the cancer treatment, practical advice and reassurance that difficulties are common.

The findings from The Netherlands (Vermeer et al., 2016), Sweden (Rasmusson & Thome, 2008), and Australia (Hordern & Street, 2007a) were supported by the findings of a seminal British study (Stead et al., 2003). Of the 12 sexually active women with ovarian cancer interviewed in a component of a mixed methods investigation, 11 felt that verbal information should be provided about sexual issues. They wanted information about whether or not sexual changes were normal, to be provided with examples of the types of problems that may

occur, reassurance that intercourse was safe and an opportunity to ask questions.

A qualitative study from the United States by Wilmoth et al. (2011) described the sexuality informational needs of 13 ovarian cancer survivors. These women wanted to know whether or not sex was permissible and whether they should consider anything in particular. They were unanimous in their view that they believed the health care provider should initiate discussions around sexuality.

In another qualitative study, content analysis was used to describe what aspects of health care were important to 14 Swedish women diagnosed with gynaecological cancer during their interaction with the health care system (Ekwall et al., 2003). The results confirmed that one of the three most important factors in determining the quality of health care was provision of care that promoted self-image and being able to talk about their sexuality.

The literature reveals contrasting perspectives on how women felt about the provision of psychosexual care between different societal contexts. For example, a grounded theory study investigated the sexual health of 11 Turkish women with gynaecological cancer in relation to characteristics such as body, sexual functioning, fertility, sexual health and how malignancy affected motherhood and wifehood (Bal et al., 2013). Despite recognised societal taboos around the topic, all the women interviewed reported feeling relaxed about discussing sexuality with a health professional (Bal et al., 2013). In contrast, a cross-sectional study in Brazil, a country known to have liberal views on sexuality, found that all 30 women with gynaecological cancer who were interviewed reported having not discussed sexuality with their oncologist and feeling ashamed to have such a conversation (Lara et al., 2012).

All of these eight studies addressing women's desire for psychosexual care, but one (Hordern & Street, 2007a) described the sexuality informational needs of women with gynaecological cancer. Common to all these findings was the women's desire for the opportunity to discuss issues of sexual health and to receive information and support from a health care provider during their cancer

care experience. As outlined earlier in this review it is acknowledged that issues of sexual health are not relevant for every woman experiencing gynaecological cancer. However, from these findings it can be seen that women want to be allowed to make that determination themselves and may do so if health providers include the topic within their routine assessment and follow-up care.

Provision of Psychosexual Care

Cancer Australia (2016) assert that women with gynaecological cancer have specific psychosexual needs including physical, emotional or psychological issues. They suggest that health professionals should be alerted to these needs in order to provide appropriate assessment and care.

A core component to achieving effective psychosexual care is the provision of an individualised assessment for every woman. McCallum et al. (2014) suggests that for gynaecological cancer care, screening and intervention should be directed around a wide range of common post-treatment difficulties. The inclusion of concerns spanning all three domains, physical, psychological and social as described by Abbott-Anderson and Kwekkeboom (2012) in their systematic review, would be essential for ensuring a holistic assessment. McCallum et al. (2014) suggest that once needs are identified, the health care provider should assess the patient's perception of their current sexual health problems as well as their expectations for what intervention could achieve. This may include symptom management and treatment strategies but for some women it may also include a discussion on their views of intimacy beyond the scope of intercourse (McCallum et al., 2014).

The referral of women to specialists in sexual health care is appropriate where the scope of knowledge and treatment is outside of the referring professional's realm, however McCallum et al. (2014) suggest that all team members should have at least a basic understanding of the etiology and treatment modalities for common problems. This would facilitate the referral process and promote individualised and effective assessment of sexual health. Having an

understanding of how treatment affects sexuality also facilitates empathy and understanding of the women's concerns and helps health professionals improve communication and the ability to offer appropriate treatments or referrals (Audette & Waterman, 2010).

Nurses provide a supportive and therapeutic role for cancer patients from pre-diagnosis, through diagnosis, treatment and survivorship. A literature review by Ayaz (2013) concludes that by following the nursing process, nurses play a key role in performing sexuality assessments and in successfully addressing the sexual problems of individuals. In the UK, 70 women treated for gynaecological cancer were surveyed in a cross-sectional study regarding their experiences of information, psychological distress and worry after treatment for gynaecological cancer (Booth et al., 2005). Women were both interviewed and asked to complete a questionnaire to establish their sources of information at the time of diagnosis and six months later when treatment was assumed to be finished. Women who received initial support from a clinical nurse specialist at the time of diagnosis showed a significantly reduced level of psychological distress six months after diagnosis ($p=0.009$). Although not a randomised controlled trial, the survey results suggest that nurses are well placed to provide supportive care to reduce distress, including psychosexual care.

A patient-centred approach is inherent in the philosophy of nursing care and places nurses in the ideal position to provide psychosexual care and significantly improve sexual health outcomes for affected women. In fact, in their commentary paper from almost two decades ago, Wilmoth and Spinelli (2000) argue that nursing care that neglects sexuality care should be regarded substandard. They cite Andrews, Goldberg and Kaplan (1996) stating that due to the existence of standards of practice relating to sexuality, it may be considered a legal standard.

In a commentary paper by Brandenburg and Bitzer (2009), it is recognised that the discussion of psychosexual issues with patients can present challenges for both patients and physicians. Some of these issues include feelings of shame by

the patient, the patient feeling that physicians do not have time to discuss sexuality issues, and not being aware that treatments for sexual dysfunction exist. For physicians, the authors suggest that some feel there is a risk of creating too much closeness with the patient by discussing intimate issues and that they will embarrass the patient by raising the issue. To address these barriers, Brandenburg and Bitzer present a ten-step approach to providing a consultation addressing sexuality issues within the text. These steps have been summarised in Table 1 presented below.

Table 1

A Stepwise Approach to Discussing Sexual Issues (Brandenburg & Bitzer, 2009)

Step 1	Addressing sexuality: use open questions to bring up the topic
Step 2	Encourage the patient to tell their story
Step 3	Differentiation questions: use questions based on the patient's narrative to gain further information
Step 4	The typical story: invite the patient to talk about their most recent sexual experience
Step 5	The descriptive diagnosis: use the information provided to describe a diagnosis
Step 6	Explore conditioning factors: use a patient-centred approach to explore possible reasons contributing to the problem
Step 7	Establish a comprehensive diagnosis of the sexual dysfunction: share these findings with the patient to create a common platform of understanding
Step 8	Define therapeutic objectives: encourage the patient to identify what they want to achieve from any therapeutic care
Step 9	Brainstorming therapeutic options: educate the patient on the available options and allow for questions and feedback
Step 10	Shared decision making about treatment: come to a common decision as to a treatment plan with the most effective outcome, lowest risk and best fit for the patient based on their values.

Note. Adapted from "The challenge of talking about sex: The importance of patient-physician interaction," by Brandenburg, U. & Bitzer, J., 2009, *Maturitas*, 63(2), 124-7. Copyright 2009 by Maturitas.

While this approach follows a biomedical model of care, the characteristics of the steps have a patient-centred focus and encourage an open and interactive discourse between the patient and physician. This model could be adapted to consultations by other key health care providers, including nurses and allied health professionals. There are some practical difficulties however. Unless the health professional intending to follow this approach was to use a visual prompt such as a checklist, remembering and following all of these steps in a consultation could be challenging.

A variety of other communication models with more discernible acronyms exist. Similar to the Brandenburg and Bitzer model, these have been developed for use by health professionals with the aim of promoting the discussion of psychosexual issues between patients and their health care providers. Hordern (2008) provides a critical appraisal of three of the most commonly cited models.

The ALARM sexual response model was developed by Andersen (1990) in the United States as a framework to help health professionals assess sexual functioning in cancer patients. The acronym stands for A – Activity, L – Libido/Desire, A – Arousal and orgasm, R- Resolution and M – Medical history. While the model is referred to by literature discussing the assessment of sexuality for people with cancer (Stabile, Gunn, Sonoda & Carter, 2015; Wang, Pierdomenico, Lefkowitz & Brandt, 2015), no studies on implementation in the clinical setting or evaluation of the model's use could be found. It is critiqued by Hordern (2008) as an example of a bio-medical approach to patient sexuality. Hordern (2008) suggests that this model is directed only towards the assessment of sexual function and does not allow patients to explore sexuality from a holistic perspective.

The PLISSIT model was originally described by Annon (1976) in the United States and aims to provide a behavioural approach to the treatment of sexual

problems using four levels; **Permission, Limited Information, Specific Suggestions and Intensive Therapy**. The model has been advocated as useful in assisting health professionals to guide discussions about sexuality (Shell, 2002) and has been used for the sexual rehabilitation of women with cancer (Cleary, McCarthy & Hegarty, 2012; Faghani & Ghaffari, 2016). Hordern (2008) suggests that while this model is widely cited and may have been innovative in its era, it may now be considered outdated. The model is described as lacking a patient-centred approach and that there is no emphasis on patients as sexual beings. This contributes to a lack of reflection of the patient's experience by the health professional and limited negotiation of communication and treatment (Hordern, 2008).

A more contemporary approach described by Mick, Hughes and Cohen (2004) from the United States is the BETTER model, designed specifically for cancer nurses to assess and communicate about patient sexuality more effectively using a holistic approach. The BETTER acronym (shown in Table 2 below) aims to help engage patients in making decisions on when sexuality is discussed and focusses on education and open communication. While this model has not been evaluated by any current literature to establish evidence for its use in practice, it is advocated for by Hordern (2008) as promoting "sexuality as a lived experience, validating the impact cancer has on intimate and sexual aspects of a person's life" (p. E15) when compared with the previously described two models.

Table 2

BETTER Model for sexuality communication

B	Bring up the Topic.
E	Explain you are concerned with quality-of-life issues, including sexuality. Although you may not be able to answer all questions, you want to convey that patients can talk about any concerns they have.
T	Tell patient that you will find appropriate resources to address their concerns.

T	Timing might not seem appropriate now but acknowledge that they can ask for information at any time.
E	Educate patients about the side effects of their cancer treatments.
R	Record your assessment and interventions in patients' medical records.

Note. Reprinted from "Using the BETTER Model to assess sexuality," by Mick, J., et al., 2004, *Clinical Journal of Oncology Nursing*, 8(1), 84-86. Copyright 2004 by Clinical Journal of Oncology Nursing.

While the use of communication models of this kind can be useful, the issues around whether or not sexuality is discussed by health professionals with patients are complicated and cannot be addressed by the development of communication models alone. In order for these models to be successful, health professionals need to remember to use them and be self-motivated to use them in everyday clinical practice. In the UK, Macdowall et al. (2010, p. 332) found in a pilot study that even after introducing an electronic prompt and tool in primary care settings named "Talking of Sex", there was only a "modest increase" in the number of consultations in which sexual health was raised, from 28.1% pre-intervention (n=52/185), to 32.6% post-intervention (n=30/92). It is reported that all of this increase was attributed to nurses having raised sexual issues during their consultations and that in the post-intervention group, doctors raised sexual issues less often compared with pre-intervention. This investigation showed that the existence and encouragement to use a communication model alone was not enough to improve the provision of psychosexual care to a desired level.

There is agreement that the assessment of psychosexual issues is essential for holistic care (Ayaz, 2013; Kotronoulas et al., 2009; Magnan & Norris, 2008) and that assessing and providing this care throughout the continuum of a person's experience of cancer can significantly increase quality of life during the survivorship phase (McCallum et al., 2014). Despite this consensus however, the provision of psychosexual care is reportedly under-provided, or poorly

addressed by health professionals (Ayaz, 2013; Ferreira et al., 2015; Gilbert et al., 2016; Park et al., 2009; Saunamäki et al., 2010; Sporn et al., 2015; Stead et al., 2003).

Nurses and the Under-provision of Psychosexual Care

There is consensus amongst the international literature that psychosexual care is generally under-provided by nurses (Ayaz, 2013; Ferreira et al., 2015; Saunamäki et al., 2010) and health professionals of all disciplines (Fitch et al., 2013; Gilbert et al., 2016; Lindau, Gavriloa & Anderson, 2007; Park et al., 2009; Sporn et al., 2015; Stead et al., 2003). Studies to investigate the reasons for this gap in care will be discussed commencing with quantitative evidence, then qualitative research, ending with a review.

Three international studies adopted either a cross-sectional or correlational quantitative approach using the Sexuality Attitudes and Beliefs Survey (SABS) as a common data collection tool. The aim of this tool is to survey the attitudes and practices of nurses related to addressing patients' sexuality issues. In Michigan in the United States, Magnan and colleagues (2005) used a correlational quantitative design to survey a convenience sample of 148 nurses using the SABS tool. Of these nurses, 78.3% disagreed with the sentiment that patients expect nurses to ask about their sexual concerns. The authors recommended replicating the study on a larger sample and a year later published the results of another study that surveyed 302 nurses working across five speciality areas, including cancer care (Magnan & Reynolds, 2006). Again, they identified the highest ranked barrier to psychosexual care across all specialisations was the nurses' perception that patients do not expect nurses to address their sexuality concerns. In the original 2005 study, Magnan et al. suggested the reason for this belief held by nurses is three-fold. Firstly, they may be protecting themselves and the patient from the discomfort which could arise from discussing a socially sensitive topic. Secondly, they may be attempting to protect their own conscience from an identified disparity between knowing what their role entails and their lack of practice in fulfilling

that role. Thirdly, they may be attempting to protect the patient from discussions which they perceive could cause them anxiety. Of the 12 items in the survey, other barriers to psychosexual care identified by the American nurses in the 2006 study included a failure to make the time to address concerns, ranked as the second highest barrier, and a lack of comfort (third highest) and confidence (fifth highest) in discussing sexual issues (Magnan & Reynolds, 2006).

A second American cross-sectional study from New York incorporated a survey of 576 nurses working in a specialist cancer centre using the SABs tool (Julien et al., 2010). They similarly agreed with the sentiment that nurses believe patients do not expect nurses to ask about sexuality concerns by also ranking this as the greatest barrier to incorporating a sexual health assessment into nursing practice. Correlations between the survey items revealed that nurses who believe sexuality is too private an issue to discuss with patients customarily defer the discussion to a physician ($p < 0.001$). The authors suggested that possible reasons for these practices included a lack of training and education around sexuality and nurses having a fear of being embarrassed when discussing sexuality concerns.

A Chinese correlational study surveyed nurses using a four-part questionnaire including the SABs tool and three other newly developed sections (Zeng et al., 2012). This was the only quantitative study to specifically investigate nurses working with women with gynaecological cancer. A total of 202 nurses completed the survey across gynaecological units in six hospitals. These nurses identified facilitators to psychosexual care as having a good nurse-patient relationship (87.6%), good communication skills (82.7%) and the availability of a private environment (72.3%). Barriers identified by nurses included the perception that women had more important things to be concerned about than having sex (72.3%), the belief that sexuality care is of a low priority (71.3%) and being afraid of offending patients (69.3%). Inadequate knowledge and training relating to sexuality was also identified as a barrier by 68.8% of nurses. Of the nurses surveyed, 77% agreed that sexuality was 'too private an issue to

discuss' and 63% thought that 'most hospitalised patients are too sick to be interested in sexuality'. Interestingly though, 63% agreed that one of the responsibilities of a nurse was to give their patient permission to talk about sexual concerns. On nurses' attitudes and beliefs: 35.1% felt confident in their ability to address sexuality issues; 34.7% revealed they were comfortable discussing the topic with patients; and, 34.2% made time to discuss sexual concerns.

A cross-sectional investigation in Taiwan did not use the SABS tool but instead researchers developed their own questionnaire based on the results of a pilot study (Tsai, 2004). The tool consisted of two scales identifying facilitators and barriers for taking a sexual history. The tool was validated by a panel of experts and both facilitator and barrier scales were checked for internal consistency (0.88 and 0.91 respectively) and test-retest reliability (0.77 and 0.66 respectively). A total of 391 nurses were surveyed from three hospitals and most nurses had not attended any formal training about sexuality (88.2%) or taking a sexual history (96.7%). The top three perceived facilitators for taking a sexual history identified by nurses through the Likert scale were: (1) the need to identify if a patient's sexual history is related to the current illness (n=361 (92.3%) agreed or strongly agreed), (2) the patient expressed they had a sexual problem (n=341 (87.2%) agreed or strongly agreed), and (3) as a result of suffering a needle stick injury (n=308 (78.8%) agreed or strongly agreed). In terms of perceived barriers, nurses felt: (1) that patients were embarrassed and did not know how to answer the nurses' questions (n=358 (91.5%) agreed or strongly agreed); (2) patients did not want to talk about it as they felt it was not relevant (n=319 (81.6%) agreed or strongly agreed); and (3) patients concealed information on purpose (n=343 (87.7%) agreed or strongly agreed). The authors concluded from the results that nurses confirmed the need for further education relating to sexuality and communication skills to perform these assessments.

The results of these five studies may be limited by their methodology. Using surveys with fixed-term responses may miss important contextual information

and has the potential to bias participants with responses they may not have considered while not allowing for personalised, individual responses (Schneider, Whitehead, LoBiondo-Wood & Haber, 2016). A variety of international qualitative investigations have investigated the attitudes of health professionals working in cancer care around communicating about psychosexual issues and will now be presented.

In an Australian qualitative reflexive inquiry, 50 patients diagnosed with cancer and 32 health care professionals, including doctors, nurses and allied health professionals, were interviewed about their experiences relating to communication and sexuality. Analysis revealed two major themes: unmet needs of patients; and mismatched expectations of sexuality communication (Hordern & Street, 2007a). Common responses were conceptualised as “cluster responses” and included patients wanting information, support and practical strategies about living with sexuality changes after cancer irrespective of whether their cancer affected fertility or sexual performance. Many patients identified that their needs were not met by health professionals. In contrast, most health professionals believed that patients shared their focus on disease cure, irrespective of the emotional and physical consequences. Based on what the health professionals shared about their experience, they were found to make stereotypical assumptions about the patients’ sexuality issues based upon age, sex, diagnosis, culture and partnership status. Patients identified that health professionals made assumptions without consulting them.

In Canada, 34 health professionals working in cancer care, including physicians, nurses, social workers and radiation therapists, were interviewed in a qualitative descriptive study (Fitch et al., 2013). The purpose was to gain an increased understanding about the dialogue between cancer health professionals and patients relating to sexuality. A common theme identified that health professionals have difficulty with these conversations and they expressed personal discomfort citing a lack of training around sexuality communication. Another theme revealed how they usually waited for patients to initiate the discussion but also acknowledged that patients rarely did. When

conversations did occur, they focussed on side effects and rarely covered the emotional and personal impact of sexuality issues. The theme “Sexuality is not perceived as a priority for cancer patients” in light of their life-threatening disease, demonstrated that assumptions were made by these health professionals. Another assumption was revealed in theme three where health professionals expressed their belief that if sexuality was going to be a concern, it would happen after the conclusion of treatment and therefore they would not raise the topic during the treatment interval.

Ten nurses from Sweden were interviewed during a phenomenological study and asked to describe their perceptions on engaging in dialogue with cancer patients about sexuality (Olsson, Berglund, Larsson & Athlin, 2012). Results revealed one main category, “We should talk about sexuality – but we usually don’t” and three descriptive categories: (1) nurses felt their attitudes, knowledge and skills are impacting on their views of talking or not talking about sexuality; (2) patients’ sexual problems are the basis for dialogues; and, (3) the ward environment affects nurses’ ability to participate in a sexuality dialogue. Within the first descriptive category, nurses described their attitude that psychosexual care was the responsibility of someone else. Within these attitudes, they made assumptions around the patients’ need for psychosexual care based on where they were in their treatment regimen and the belief that patients would place a low priority on issues of sexuality. These Swedish nurses were also concerned about offending or embarrassing the patient and felt they lacked the knowledge and skills to provide psychosexual support.

Three qualitative studies explored the perceptions of health professionals, including nurses, working specifically with women with gynaecological cancer. In the United Kingdom, 16 doctors and 27 nurses treating women with ovarian cancer were interviewed in a qualitative study using content analysis (Stead et al., 2003). Only nine (21%) of these health professionals discussed sexual matters with their patients even though almost all of them (98%) agreed that they should be discussed. A summary of comments revealed how they identified barriers to discussing sexual concerns with women with ovarian

cancer. The health professionals suggested that communication about sexuality issues was not their responsibility, that they were embarrassed and that they lacked the knowledge, experience and resources to provide psychosexual support.

A qualitative study using content analysis in Brazil investigated the barriers for the inclusion of sexuality in nursing care of women with cancer (Ferreira et al., 2015). Sixteen nurses, nursing technicians and nursing assistants were interviewed and findings were similar to the UK study by Stead et al. (2003). Three themes emerged: “barriers related to the biomedical model”; “barriers related to institutional dynamics”; and “barriers related to social interpretations of sexuality”. The nurses shared that care under the biomedical model was focussed on cure of the disease and failed to prioritise holistic needs. These nurses also described social barriers identifying the negative influence that cultural values and gender issues have on the discussion of sexuality which is considered a private topic.

In The Netherlands, 30 health professionals who care for women with gynaecological cancer were interviewed in a qualitative study using a framework approach (Vermeer et al., 2015). The interview topics were used to identify the patient population and problems experienced, to assess their current practices, to identify barriers to psychosexual support and to establish their needs for training and assistance. These oncologists and nurses identified that embarrassment and lack of time hindered their ability to provide psychosexual support to gynaecological cancer survivors. All the participants reported discussing sexuality with women at least once. About half indicated they provided specific suggestions for sexual concerns however they rarely referred the women to a sexologist. These health professionals suggested they needed more skills training, more information for patients and the integration of standardised psychosexual support within gynaecological cancer care.

In Turkey in 2013, Ayaz published a review article examining the literature on addressing sexuality and sexual health in nursing practice. Whilst the exact

number of articles reviewed is not stipulated, the reference list of 32 was incorporated to describe a variety of methods and tools which nurses may use to assist them in practicing psychosexual care. In doing so, the author has also highlighted difficulties experienced and concludes that nurses often do not perform sexuality assessments in practice despite acknowledging they are part of holistic care and considered part of their professional role.

Although the international studies presented represent a variety of research designs, their findings reflect similarities around specific aspects of providing psychosexual care to cancer patients. The issue of experiencing discomfort as well as perceptions of lack of education and training in psychosexual care appear to be shared barriers amongst health professionals. At the same time, the diversity of responses from health professionals internationally, including nurses, again reiterates the unique nature of perceptions of psychosexual care amongst differing cultural contexts. Lee et al. (2015) declare in their phenomenological study of women's sexual experience of Taiwanese women after treatment for gynaecological cancer, that studying sexuality should be within the sociocultural context as it influences the construction of sex. Examining the issues relevant to health professionals locally is equally important in order to devise solutions appropriate to the professional development needs of clinicians.

The Hordern and Street (2007a) study is the only one previously conducted in Australia to investigate the attitudes and experiences of health professionals communicating with cancer patients about intimacy and sexuality. There is currently no published literature relating specifically to Australian nurses or Australian women with gynaecological cancer. As in all countries, Australians are influenced by the representations, beliefs and practices embedded within their culture at any given time and Ussher et al. (2013a) describe that social constructionist theorists support this notion. Australia is a diverse and multicultural community of 25 million people geographically spread across 7.7 million square kilometres (Australian Bureau of Statistics, 2018). Census data from 2016 cites that 35.4% of the population were born in another country,

predominantly from Europe, Africa or Asia. These cultural and geographical influences have the potential to affect the construct of sexuality however it is not possible to make these conclusions or compare them with other countries without evidence to support it.

Psychosexual Care Education Resources for Health Professionals

Based on the literature discussed above, there is consensus on the need to improve the provision of psychosexual care. This need was drawn from the evidence identified by cancer patients, including women with gynaecological cancer, that health professionals do not appear to be meeting the need for this care. From a review of the literature around health professionals' attitudes and learning needs around psychosexual care, it is apparent that participation in education and training on sexuality and psychosexual care is recognised as an essential strategy to improve quality of care by increasing both knowledge and confidence. Despite evidence highlighting this educational need, there is little literature available on the implementation or evaluation of education interventions and practical strategies for health professionals and none relating to dedicated psychosexual care training for gynaecological cancer nurses.

One Taiwanese mixed methods study claims to be the first of its kind to develop and evaluate an evidence-based sexuality training program for nurses (Sung, Jiang, Chen & Chao, 2016). Nurses from all areas of a psychiatric and general community hospital in Taiwan were invited to participate. Firstly, 16 nurses participated in an exploratory descriptive process via focus groups to assess their perceptions and educational needs concerning sexual health care. In the second stage, nurses were randomly assigned so that 59 nurses participated in the experimental group and 58 in the control group. The intervention involved the participation of nurses in a training program that focussed on their knowledge, attitudes and self-efficacy of sexual health care practice. Nurses were required to attend a total of eight, two-hour education sessions which included lectures, media, case studies, role-play, group discussions and brainstorming. The content of the program was developed from data retrieved

in focus group sessions with the recruited nurses. Overall, the authors demonstrated significant improvements in knowledge ($\beta = -0.12$, $p < 0.01$) and attitude ($\beta = -0.25$, $p < 0.05$) scores when comparing the experimental group to the control group. While the self-efficacy scores of the experimental group increased significantly ($\beta = 0.73$, $p < 0.001$), these scores were not significantly different when compared to the control group ($p = 0.179$).

In Australia, Philp, Barnett, D'Abrew and White (2017) used a mixed methods evaluation framework to report on the development and evaluation of a professional development intervention aimed at improving the confidence of 62 registered nurses working the area of gynaecological cancer. Pre and post-intervention questionnaires were used to determine the nurses' views on program content and assess any change in their confidence before and after participation. The intervention was delivered as a one-week training module consisting of a four-day theory program delivered by experts speaking on approximately 20-23 areas, and one day of clinical visits to a gynaecological oncology unit at a metropolitan teaching hospital. There is no further inclusion of information relating specifically to the psychosexual aspects of the training course. Participants were asked to rate their confidence in nine areas including "Supporting a patient who is having difficulties relating to altered body image and effects on sexuality and sexual function", as well as to outline their areas of least and greatest confidence for each of the nine topics as open-ended responses. Overall, the participating nurses rated an improvement in their confidence relating to gynaecological cancer care immediately after the course ($z = -6.515$, $p < 0.001$) and 12 months after completion ($z = -4.155$, $p < 0.001$), compared with pre-course confidence levels. In relation to confidence in the area of sexuality support, approximately one-third of nurses reported a great degree of confidence in discussing issues and building rapport before attending the course. Areas where confidence was lacking included sexual dysfunction, sexuality, lack of knowledge, when to involve family, and the fact that patients do not often raise the issue. There was no further qualitative data relevant to psychosexual care reported for post-course confidence.

Another Australian education intervention which was not reported in published literature was an online educational resource developed by Cancer Australia in 2010, “The Psychosexual Care of Women Affected by Gynaecological Cancers”. The aim of this resource was to address gaps in health professional knowledge around psychosexual issues experienced by women with gynaecological cancer. The learning outcomes of this resource are presented in Table 3. Learning modules and video case studies were provided on a freely available website to assist health professionals to develop knowledge and skills around the provision of psychosexual care for women and their partners.

Table 3

Learning Outcomes of Psychosexual Care of Women affected by Gynaecological Cancers (PSGC) Resource (Cancer Australia, 2010)

PSGC Learning Outcomes

Participants will be able to:

- Describe the dimensions of sexuality.
 - Identify key elements of frameworks for psychosexual care.
 - Describe the effects of gynaecological cancers and their various treatments on physical, psychological, social and sexual functioning.
 - Understand the key principles of psychosexual communication.
 - Identify health professionals and support services for referring women and their partners for psychosexual care.
 - Discuss the key elements of a comprehensive psychosexual assessment.
 - Identify interventions appropriate for specific psychosexual concerns.
 - Discuss the evidence that underpins specific psychosexual care interventions.
-

Information about the resource was disseminated through email newsletters from Cancer Australia and the delivery of presentations and workshops at national meetings for associations including the Clinical Oncology Society of

Australia and the Cancer Nurses' Society of Australia. National gynaecological cancer leaders and educators were also invited by Cancer Australia to attend face-to-face 'Train the Trainer' sessions in Sydney which provided information and support for the implementation of the resource and associated educational interventions in health service settings across Australia. Following this comprehensive national implementation phase, no further evaluation of the use of the resource has been published. The effectiveness of this educational strategy to influence clinical care and patient outcomes is therefore still unknown. As of 2016, this online resource has been removed from the Cancer Australia website citing "necessary website maintenance tasks".

Following the online intervention presented in the previous paragraph, a brochure resource titled "Intimacy and sexuality for women with gynaecological cancer – starting a conversation" was also published by Cancer Australia in 2012. The resource was developed to support women and partners in addressing psychosexual issues after a gynaecological cancer diagnosis. The brochure is available for individuals and institutions to order for free from the Cancer Australia website.

At the tertiary women's hospital in Western Australia, the site for this research study, the aforementioned Cancer Australia resources were used to implement workshops and study days from 2012 until 2017 with the aim of addressing the need for more education around the provision of psychosexual care. Over these six years, annual professional development study days on "Psychosexual Care of Women with Gynaecological Cancer" have been facilitated by a Nurse Educator with attendance by 85 nursing and allied health staff. In addition, three shorter ward-based in-service education sessions attended by 20 nurses and allied health staff were provided in 2012 to cover basic principles of psychosexual care and encourage use of the online resource. Evaluation was conducted on the participants' level of knowledge and confidence around understanding and communicating the psychosexual effects of gynaecological cancer at these educational events. All participants agreed that their knowledge and confidence on the topic of psychosexual care had improved as a result of attending. While

this evaluation was conducted at the time of these events, no further evaluation was pursued on whether there was any effect on clinical practice or outcomes as a result of attending. A link to the Cancer Australia online resource was made available on the educational hub website of the hospital, however it is not possible to assess how many staff have accessed the resource or whether it's use has had an effect on practice or outcomes.

Summary

Gynaecological cancer can have a profound impact on a woman's sexuality and it is known from the evidence that women want to be given the opportunity to discuss issues of psychosexual care with health professionals, including nurses. Despite this expressed need by women, there is an international consensus that psychosexual care is under-provided by health professionals and that a variety of barriers to the provision of this care exist including a lack of education and training opportunities.

Sexuality is a unique and individual construct influenced by a wide variety of factors including the sociocultural context within which people live. It is suggested that the study of psychosexual concepts should be within a patient's unique sociocultural environment and as such, results of studies from other sociocultural contexts may not translate internationally (Lee et al., 2015). The same argument can be presented around the perceptions of health professionals on the provision of psychosexual care. Sociocultural factors differ between cultures internationally and have the potential to influence the provision of care within a specific context.

To date, there is no available literature investigating the attitudes and perceptions of health professionals, including nurses, on the provision of psychosexual care to women with gynaecological cancer in Australia. In order to address this gap in the literature, the aim of this study was to investigate the perceptions of Western Australian nurses around the provision of psychosexual care for women undergoing gynaecological cancer treatment. Next, chapter three will provide an overview of the methods employed in this study.

CHAPTER THREE: METHODS

Chapter Overview

In this chapter the author will describe how the study investigating nurses' perceptions of providing psychosexual care to women undergoing treatment for gynaecological cancer was conducted using a qualitative descriptive design.

Firstly, research terminology used throughout the chapter will be defined to provide clarity of the terms used for the reader. Next, the positivist and naturalistic research paradigms are critically examined to clarify why a qualitative descriptive design was determined the most suitable approach for this study. Research designs aligned with the selected paradigm are explored to match the study purpose/aim with the most suitable research design. The author will discuss the chosen design and provide examples of the design's use in a gynaecological health care context.

A detailed description of the research process followed during this study will then be provided. The setting and participants of the study will be outlined including information on the demographic data collected from nurse participants. Following on, a description of the recruitment methods and how the data was collected will be explained. Next, the steps used for data analysis will be presented along with an in-text sample to exemplify how this process was conducted. Finally, information on the ethical considerations regarded in this study will be detailed.

Research Terminology

Terminology used when describing the process of conducting a research study can be confusing if not defined at the outset. As such, the following definitions are provided to clarify to the reader how a variety of terms will be used throughout this chapter.

Research design: The planning procedures for conducting studies. These procedures may be drawn up as a set of instructions for gathering evidence and

interpreting it. It can be described as the way in which the research was conducted, e.g. what happened during the study (Holosko & Thyer, 2011; Vogt & Johnson, 2011).

Research method: The main approach that is taken to conduct the study, such as experimental, descriptive, grounded theory, case study, quantitative, qualitative, or mixed methods (Holosko & Thyer, 2011; Vogt & Johnson, 2011).

Method(s): The tools used for data collection, such as interviews, focus groups, questionnaires, or observation.

Paradigms in Research: Positivist and Naturalistic

A paradigm is a position or view of understanding about the world in which we live (Schneider et al., 2016). Paradigms within research describe philosophical assumptions or beliefs shared by researchers in order to guide their inquiry (Schneider et al., 2016). There are two main classifications widely accepted by researchers, referred to as positivist/post-positivist or naturalistic/constructivist paradigms.

Positivism describes a view that facts about the world exist as a scientifically measurable variable and are not influenced by the context in which they occur; the facts exist and are awaiting discovery (Krauss, 2005; Schneider et al., 2016). A positivist position proposes an understanding that the goal of science is to prove what we can observe and measure and that data is value-free, not influenced by observation and doesn't occur by chance (Krauss, 2005; Schneider et al., 2016). Positivism is recognised as a traditional scientific approach and is associated with quantitative research designs such as clinical trials and cohort studies (Polit & Beck, 2014; Schneider et al., 2016).

Quantitative research methods involve the testing of hypothesis or theory by prediction. Objective variables and causal relationships are measured by observation and are tested to establish support or non-support for a prediction or hypothesis (Schneider et al., 2016).

The naturalistic/constructivist paradigm is a more recent alternative view that considers there is no objective reality, that multiple realities exist and are influenced by their context (Streubert & Carpenter, 2011). In constructivism, reality is constructed by the humans experiencing the phenomenon of interest (Krauss, 2005) and may therefore have many different meanings as a result. This paradigm is representative of qualitative research and involves the researcher being an engaged instrument within the investigation, rather than an independent outside observer as in quantitative research.

Table 4 below from Streubert and Carpenter (2011) offers a comparison between the characteristics of quantitative and qualitative research. This comparison demonstrates the characteristics influencing these research methods with either the positivist or naturalistic/constructivist paradigms at their core. The researcher must consider these characteristics when determining the suitability of a method for a proposed study.

Table 4

Comparison of Quantitative and Qualitative Research Methods

Quantitative	Qualitative
Objective	Subjectivity valued
One reality	Multiple realities
Reduction, control, prediction	Discovery, description, understanding
Measurable	Interpretative
Mechanistic	Organismic
Parts equal the whole	Whole is greater than the parts
Report statistical analyses	Report rich narrative
Researcher separate	Researcher part of research process
Subjects	Participants
Context free	Context dependent

Note: Reprinted from *Qualitative research in nursing: advancing the humanistic imperative* (p. 20), by Streubert, H. J., and Carpenter, D. R., 2011, Philadelphia: Wolters Kluwer Health Lippincott Williams & Wilkins. Copyright 2011 by “Wolters Kluwer Health Lippincott Williams & Wilkins”.

Choosing a research paradigm

In selecting an appropriate paradigm that is aligned with qualitative or quantitative research and a suitable research design for an investigation, it is suggested that a researcher should consider the following:

- 1) The purpose of the research and questions being asked
- 2) The nature of the issue or problem being investigated
- 3) Which paradigm is likely to offer the ‘best fit’ for the process and outcomes
- 4) The knowledge and experience of the researcher
- 5) The need, or not, for generalisability or transferability of the results to other populations (Schneider et al., 2016, p. 22).

It is essential that selection of a paradigm that informs the preference for quantitative or qualitative research is driven by the investigation itself and may only be done so by examining such points before commencement. Adopting a research method and forcing it to ‘fit’ the investigation may jeopardise the integrity of the study and result in the loss of its original purpose (Leedy & Ormrod, 2015).

The aim of this investigation was to gain insight into how Western Australian nurses conceptualise the provision of psychosexual care for women undergoing gynaecological cancer treatment, and to identify what they perceive to be facilitators and barriers to this care. The nature of human perception is such that it is not possible to be separated from the reality within which the subject exists (Schneider et al., 2016). Perception involves applying meaning and understanding to a phenomenon, a process that positivism and therefore quantitative research does not allow for. As described in Table 4 above,

qualitative research methods are best suited where the subjectivity of data is valued, recognises that multiple realities of the research participants (i.e. nurses) exist, is aimed at discovering, describing and understanding the data collected and is dependent on the context around which the participants exist (Streubert & Carpenter, 2011). In comparison, quantitative research assumes one reality, is measurable, controlled and context free. These qualities were not considered to align with the investigation's aim of understanding the nurses' conceptualisation of their provision of psychosexual care. It is for this reason that a qualitative approach was chosen for this investigation.

Choosing a qualitative design

A qualitative research design was chosen to examine the perceptions of Western Australian nurses around the provision of psychosexual care for women undergoing gynaecological cancer treatment. Qualitative research is useful when enquiry of the data has no pre-conceived hypothesis and when quantitative measures and statistical analysis do not fit the problem (Creswell, 2013). Rather than attempting to find evidence to test a hypothesis and support or refute a theory, findings are formed by examining the data and building upon evidence throughout the process of analysis.

Qualitative research is common in health science research and is suggested by Creswell (2013) as preferable when researchers aim to (a) share individual stories, (b) write in a literary, flexible style, (c) understand the context or setting of issues, (d) explain mechanisms or lineages in causal theories, (e) develop theories, and (f) when traditional quantitative statistical analyses would not generate findings to address the problem.

Traditionally five qualitative research methods exist: narrative, phenomenological, grounded theory, case study and ethnography. Each of these research methods will be described below along with a justification as to why they were not suitable for use in this investigation. These points are summarised in Table 5.

Table 5

Common Qualitative Methods

Method	Method Description & Purpose	Justification for not using in this study
Narrative	The aim is to explore the stories of individuals and understand how they use these to make sense of events in their lives.	The aim of this study was to describe the perceptions of a group of nurses relating to a specific nursing point of care.
Phenomenological	The purpose is to understand the essence of an experience, or to attach meaning to an event.	For this study, the aim was to describe how nurses felt about the provision of psychosexual care but not to attach meaning to the experience of providing the care.
Grounded theory	The purpose is to develop a theoretical proposition or model from the data.	The aim was not to develop a theory but to describe the views of the participants within their context.

Ethnography	The focus is on the common aspects of human activity from an anthropological and sociological viewpoint. Its purpose is to describe and interpret shared patterns within the group.	In this study, the participants' patterns of activity as part of a collective nursing cultural group were not used to develop the findings.
Case Study	The aim is to develop an in-depth description or analysis of one or a few individuals using multiple data sources.	The aim in this study was to develop a comprehensive summary of a group of individuals (gynaecological nurses) rather than an in-depth description of just one or two cases.

Note: Adapted from *Research design: qualitative, quantitative and mixed methods approaches*. (pp. 104-6), by Creswell, J., 2013, Thousand Oaks: Sage Publications. Copyright 2013 by "Sage Publications", and *Essentials of nursing research: appraising evidence for nursing practice*. (pp. 48-9), by Polit, D.F., & Beck, C.T. 2014, Philadelphia: Wolters Kluwer Health Lippincott Williams & Wilkins. Copyright 2011 by "Wolters Kluwer Health Lippincott Williams & Wilkins".

The aim of narrative research is to explore the stories of individuals and to understand how they make sense of events in their lives (Polit & Beck, 2014). It is based on the notion that individuals use stories to make sense of their world and communicate meaning through narration. Typically, one or more individuals are studied using interviews and documents (Creswell, 2013). In examining the perceptions of nurses in this study, the data will be collected relating to a specific point of care within their nursing duties and they will not

be asked to describe the influence of their life story on that care. Some nurses may use stories or scenarios to describe their experiences around providing psychosexual care but they will not be asked to try to make sense of the events. Narrative research was therefore deemed inappropriate to address the aims of this study.

Phenomenological qualitative research is focussed on understanding an experience or lived phenomenon by attaching meaning to the experience (Streubert & Carpenter, 2011). During analysis, statements with significance are read with the purpose of describing the “essence” of the experience. Participants are usually a group of individuals who have shared the same experience and data is collected primarily by interviews, as was used in this investigation (Creswell, 2013). There are two main types of phenomenology known as descriptive phenomenology and interpretive phenomenology (Polit & Beck, 2014). Interpretive phenomenology is concerned with interpreting and understanding the lived human experience. Descriptive phenomenology relates to describing what we know as humans and how this relates to the human experience. As a traditional qualitative research method, descriptive phenomenology could have been considered for this study in relation to its objective to describe what is known. It was not chosen however, as the aim was to gain insight into how Western Australian nurses conceptualise the provision of psychosexual care for women undergoing gynaecological cancer treatment and to identify what they perceive to be facilitators and barriers to this care, not to attribute meaning to their experience of providing psychosexual care.

The aim of a study with grounded theory design is to develop a theoretical proposition or model and is often illustrated in a figure proposing relationships between categories (Creswell, 2013; Polit & Beck, 2014). The researcher focusses on studying a particular process or action and collects data from participants primarily using interviews. Data analysis is conducted through coding, simply described as a process by which data is attributed codes and categories based upon “social psychological processes grounded in real-world observations” (Polit & Beck, 2014, p. 381). Identified codes are then grouped

together to form categories. In the case of this investigation, the aim of the study was not to generate theory but to describe the perceptions identified by the nurses. To address the aim of the proposed study, grounded theory was deemed to not be an appropriate design for this study.

The aim of ethnography is to describe and interpret data collected from a group that share similar patterns of human activity, or culture (Creswell, 2013; Polit & Beck, 2014). Data is collected primarily through interview but also observation and other sources. It could be said that nurses working in a similar setting may share a culture by working within the same context, in that they share ideals and values such as beneficence (doing good) and non-maleficence (doing no harm) whilst caring for people. However, the nurses in this investigation will not be asked to comment on aspects of their nursing culture that influenced provision of psychosexual care. For this reason, ethnography was not considered an appropriate design for this investigation.

The final method of the traditional qualitative designs considered is case study. In this study design, multiple sources of data are collected in order to provide an in-depth understanding of one or more cases. Analysis is conducted by describing the case and developing themes of the case, as well as cross-case themes. In this investigation, the aim was to comprehensively summarise the perceptions and conceptualisations of a group of nurses, not an in-depth description of just one or two. As such, case study was not appropriate to meet the aims of this study.

Although phenomenological, grounded theory or ethnographic designs in particular are widely used for qualitative research, there are increasing instances where these designs do not address the research question or aim of particular studies; they are not the 'best fit'. Two seminal works by Sandelowski in 2000 and 2010 famously describe the method claimed as "qualitative description". It is argued to be an existing methodology in its own right, and worthy of equal standing to other methodologies as an appropriate design for certain purposes (Sandelowski, 2000).

Qualitative description is based on naturalistic inquiry theory which commits to studying something in its natural, or truthful state (Colorafi & Evans, 2016; Sandelowski, 2000). In saying that, Sandelowski also clarifies that qualitative descriptive studies may also legitimately display hues, tones or textures of other approaches as can be the case when studies adopt any qualitative method. The method is characterised by adopting low-inference interpretation of the data resulting in a comprehensive summary of events in their everyday terms. This point is not to be confused with a lack of interpretation altogether. This is explained further by Sandelowski (2010) where she explains that no research is non-interpretative and qualitative descriptive studies produce findings close to the data as it was provided by the participants.

Sandelowski (2010) describes qualitative description as useful for researchers who wish to know about the who, what and where of events or phenomena. It is therefore appropriate when examining the perceptions of nurses as it focusses on the experiences of individuals, and allows rich, authentic description of patient-professional interactions (Neergaard, Olesen, Andersen & Sondergaard, 2009; Sandelowski, 2010). Colorafi and Evans (2016) also agree, conferring the ability of this method to provide factual responses from participants about how they feel about the phenomenon, the reasons behind their practice, who is involved and what factors can facilitate or hinder the subject in question. The researcher is able to stay close to the data without being influenced by restrictive pre-determined theoretical frameworks. It also allows for more easily attained consensus amongst the research team by focussing on the perceptions and the interpretation of meaning participants give to particular experiences. Once analysed, researchers then aim to describe these perceptions in an organised and coherent manner.

Qualitative description, also known as interpretive descriptive or descriptive exploratory research is described as an emerging trend in qualitative research methodology (Schneider et al., 2016). Two examples of recent international studies in the area of gynaecology are described below. Both of these adopted qualitative description as their chosen methodology.

In 2014, a Danish study investigated the supportive care needs of women with gynaecological cancer, and their relatives, in the prediagnostic period (Holt, Hansen & Mogensen, 2014). The authors state their choice for adopting qualitative description as the study's method was based around their aim to present the participants' points of view and stay close to the data, citing Sandelowski (2000). Data collection occurred over a three-month period, when 16 women and 16 relatives were interviewed using a semi-structured format. Analysis resulted in the formation of 13 themes, six derived from the patients' interviews and seven from interviews with the relatives. The authors provided a rich description of their processes of analysis and rigour to ensure credibility of their results (Holt et al., 2014).

Canadian researchers Etchegary, Dicks, Watkins, Alani and Dawson (2015) interviewed women who were known Lynch syndrome mutation carriers about their decisions relating to prophylactic gynaecological surgery. Women who carry this mutation have a significantly increased risk of developing cancer, in particular colorectal, endometrial and ovarian cancer. The aim of this study was to investigate and summarise the surgical decisions of these women. Qualitative description was chosen as the method due to its theoretical basis of natural inquiry and its ability to present the data in the language of the participants, resulting in a comprehensive summary of the event in question (Etchegary et al., 2015). The findings were presented as two themes describing firstly, the factors associated with prophylactic gynaecological surgery decisions, and secondly, women's perceptions about pre-surgical information provision and needs. This example describes the use of qualitative description as a means of investigating the perceptions of individuals around a particular circumstance or event and thus demonstrates similarities to the investigation that is the subject of this thesis. Themes and subthemes are presented as an organised summary of the participants' responses and are supported by direct quotes from the interview data. The discussion examines the possible factors surrounding the participants' responses and provides recommendations to help improve care (Etchegary et al., 2015).

These examples demonstrate that the use of qualitative descriptive design is not unprecedented in the area of health care and gynaecology. Furthermore, evidence has been presented around its justification in the use of studies investigating the perceptions of health care professionals such as nurses, particularly when seeking to describe those perceptions in a voice as similar to the participants as possible. As such, qualitative description was chosen as the design to best fit the aims of this study.

The Author as a Methodological Instrument

One of the characteristics of qualitative research outlined earlier, is the engagement of the researcher within the investigation as an active instrument of the research process, rather than a passive observer of the data as it presents itself (Streubert & Carpenter, 2011). As such, it is acknowledged that in spite of all efforts to remain open-minded and objective during the process, the clinical experience of the researcher will likely influence, at least to some extent, the direction and tone of the investigation. By outlining a biographical profile of the author and primary researcher, the author aims to openly disclose professional experiences which may have influenced this investigation.

The author completed a Bachelor of Science (Human Biology) before gaining professional experience for a short period in the field of medical science. After travelling and working in the area of legal administration support, she returned to Australia to undertake a degree in nursing. The author had always been drawn towards working in the area of women's health and as such, commenced employment after graduation as a registered nurse at the tertiary women's hospital in Perth, Western Australia. Over two years, the author gained experience in a range of gynaecological clinical areas in the hospital. The author then took on an opportunity to share her passion for gynaecological nursing by commencing a position in staff development on the gynaecology ward. During this time, the author also completed graduate certificates in women's health and health professional education. After returning from a period of parental leave, the author then commenced a position as Nurse Educator where she continued

to work closely with graduate nurses and substantive staff working in the gynaecology clinical areas by providing educational support and professional development opportunities. More recently she took on an additional part-time role in the capacity of gynaecology nurse research.

In these educator and research roles, the author was involved in the facilitation and delivery of education relating to psychosexual care for women with gynaecological cancer and as such acts as an advocate for the delivery of such care. The author acknowledged this influence and used the process of reflection to facilitate awareness of assumptions around the provision of psychosexual care. Before commencing data analysis, the author documented thoughts, feelings and assumptions around this phenomenon in a reflective journal. The use of a reflexive journal is said to be a common strategy to assist researchers in identifying pre-conceived beliefs and opinions and to help bracket out these presuppositions in order to face the data in a pure form (Polit & Beck, 2014). In documenting these thoughts, the author similarly aimed to set them aside in order to remain objective and open to the perceptions and experiences shared by the study participants.

Setting

This study was conducted at a public tertiary women's hospital, the primary referral centre of care for women diagnosed with a gynaecological cancer in Western Australia. In Australia, health care is provided within either the public or private health system. All Australians are entitled to access health care under the public system however they can also choose to pay to access private care with their choice of treating physician. In this public health setting, approximately 270 women are treated for gynaecological cancer each year and care is provided under a holistic model of care (Government of Western Australia, Department of Health, 2009) whereby nurses play a key role in the multidisciplinary team.

Registered nurses work in a number of clinical areas in the hospital, providing both supportive and clinical care to women diagnosed with, or suspected to

have, gynaecological cancer. Ambulatory care at the hospital is provided by a multidisciplinary team in a variety of outpatient clinics. Registered nurses play key roles in all of these clinics including diagnostic services such as colposcopy and hysteroscopy, surgical pre-admission clinics, nurse-led cancer care coordination, menopause symptoms after cancer clinic, sexual wellness clinic and the oncology clinic. Clinical care is provided in the gynaecological clinical care unit in a variety of settings including the day surgery unit where patients are admitted prior to surgery, the operating theatre for perioperative care, and the gynaecology ward where patients stay for post-operative care until they are well enough to return home.

Participants

Purposeful sampling was adopted in order to achieve a greater understanding of the topic in question. In purposeful sampling, “participants are selected for the purpose of describing an experience in which they have participated” (Streubert & Carpenter, 2011, p 28.) and are selected based on the researcher’s judgement of who will be the most informative with the relevant clinical experience around the area of interest (Polit & Beck, 2014; Vogt & Johnson, 2011). Registered nurses working in both the outpatient clinics and gynaecology ward at the setting, were invited to participate in the study. Inclusion criteria were that nurses were required to have at least 12 months nursing experience and be currently working with women experiencing gynaecological cancer. Exclusion criteria were nurses with less than 12 months nursing experience (i.e. graduate nurses) and nurses not currently working with women experiencing gynaecological cancer. The rationale behind requiring a minimum of 12 months nursing experience was to ensure the nurses had developed assessment skills beyond those of a beginner practitioner. This would include assessment of psychosocial issues, such as sexuality concerns.

Basic demographic data of the participants was collected, including qualification level, whether they worked primarily in a ward or outpatient setting, number of years nursing and gynaecology experience and whether they had previously

participated in psychosexual care training (Appendix A). Transferability is the ability to apply the findings of one setting to another and as the setting was the public tertiary women's hospital located in a metropolitan Western Australian city, the readers will need to determine how transferable the findings are to their setting (Colorafi & Evans, 2016). In order for the readers to assess the transferability of findings, it is important that rich description of the study context is provided. Therefore, transferring the findings of this study to other care contexts must involve consideration of the influence of Australian cultural and societal views on sexuality. In addition, the broad socio-economic status of the participants as middle-income health professionals may have influenced their perspectives on sexuality.

Recruitment was conducted by disseminating information about the study through various means. Meetings were arranged with relevant nursing managers to discuss the study and inform them of the relevance of the study to the nurses working in their areas. Emails were sent to 60 nurses who met the study's inclusion criteria, in that they were currently working in either the gynaecology outpatient clinics or gynaecology ward and had at least 12 months nursing experience. Posters were placed in gynaecology clinical areas with information on the study and how nurses interested in participating could find out more. Finally, the author attended relevant meetings to inform nurses about the upcoming study. Nurses who expressed interest were provided with a copy of the information sheet (Appendix B) and if willing to be interviewed, a suitable date, time and venue was organised. In all, 17 nurses expressed interest in participating, met the inclusion criteria and all were interviewed.

Data Collection

Semi-structured interviews were chosen for data collection to maximise the amount and quality of information provided. In previous studies where a survey design has been utilised (Julien et al., 2010; Magnan & Reynolds, 2006; Zeng et al., 2012), responses were limited by pre-determined options and did not allow for personalised, individual replies. An interview guide (Appendix C)

was developed by the authors outlining a series of open-ended questions and are summarised in Table 6 below.

Table 6

Main Interview Questions

1	Tell me about how you ask questions about sexuality and psychosexual care with a woman undergoing treatment for gynaecological cancer.
2	How confident do you feel talking with the woman about her sexuality?
3	Can you describe factors that facilitate your ability to ask questions about sexuality and psychosexual care of women undergoing treatment for gynaecological cancer?
4	Can you describe barriers to you asking questions about sexuality and psychosexual care of women undergoing treatment for gynaecological cancer?
5	Can you recall a scenario where you have discussed sexuality or psychosexual care with a woman undergoing gynaecological cancer treatment? Could you please share the scenario?
6	Is there anything else you want to add?

Questions were chosen for their capacity to encourage participants to openly share perceptions and experiences related to their nursing care as well as facilitators and barriers to providing psychosexual care. In addition, participants were asked to describe a scenario where they discussed sexuality or psychosexual care with a woman undergoing gynaecological oncology treatment. Additional prompt questions were used to encourage elaboration (Appendix C).

As outlined earlier, the author is a registered nurse working at the study setting and as such had previously worked in a clinical and educational role alongside many of the potential research participants. As part of these roles, the author is an active advocate in the delivery of psychosexual care for women with gynaecological cancer. It was acknowledged this influence had the potential to create bias during the interview process whereby participants may have felt

inclined to adopt a similar position or focus more on positive experiences in this area. In an attempt to avoid this potential bias, another research nurse from the university affiliated with the investigation agreed to conduct the interviews with participants. Many of the potential participants were familiar with the interviewer as she was concurrently undertaking an unrelated research study and therefore had established some professional rapport with them. However, the interviewer had no previous clinical affiliation with the participants or overt disposition about the subject of psychosexual care.

Participants provided informed consent prior to the interview (Appendix D). Demographic data was also collected, including qualification level, whether they worked in a ward or outpatient setting, number of years of nursing and gynaecology nursing experience and whether or not participants had participated in any relevant professional development education relating to psychosexual care within the past three years (Appendix A).

Interviews were digitally recorded and transcribed for analysis. During transcription, each participant was assigned a number and no identifiable names were included. The consent forms were kept separately and were not made available to the author. All 17 interviews were conducted over five months from February to July 2015. Interview length ranged from 6:52 minutes to 33:46 minutes (average 18:41 minutes) generating 123 pages of transcripts and 48,808 words. Interviews ceased once data saturation had been achieved, in that no new data was being gained and no new codes were being generated (Fusch & Ness, 2015).

Data Analysis

Data analysis was conducted concurrently throughout the data collection period. In qualitative descriptive analysis, there is low-inference interpretation to ensure the researcher stays close to the data (Neergaard et al., 2009; Sandelowski, 2000). This enables the analysed data to remain in a language similar to the informants' own language and produces a straight descriptive

summary free from theoretical strings or philosophical commitments (Neergaard et al., 2009; Sandelowski, 2000).

The author followed a systematic thematic analytical process summarised below (Braun & Clarke, 2006 & Creswell, 2013):

1. Transcripts were initially read 3 times to gain familiarity.
2. On the third read, transcripts were reviewed for selection of key phrases focusing upon the question ‘what is that about?’
3. After analysing the first 4 interviews, topics were generated to cluster similar ideas.
4. Topics were abbreviated to codes and used to code future interview transcripts and as new ideas emerged within the data, new codes were generated.
5. Codes were attributed descriptive wording and formed into categories by clustering similar codes together.
6. All existing data was recoded with these categories.

Primary data analysis was commenced in Microsoft Word where interview transcripts were converted into a table format with an extra column added to the right-hand side. Transcripts were read 3 times and on the third time, key phrases were highlighted and copied into the right-hand column. After analysing the first four interviews, these key phrases were revisited and notes were added answering the question, “what is that about?” (See Figure 1 below). As notes or codes were attached to key phrases, the author noticed that commonalities were forming and codes began repeating throughout subsequent interviews.

<p>P4 Yeah so when initially you ask that question it's a bit awkward for most patients they'll be like oh you know, you see the facial changes, you'll see how they respond they're like oh, um or if they're saying oh yeah I've been addressed already, somebody's spoken to me already, maybe if they've been SMS, the Surgical Menopause Service or if they've</p>	<p>Non-verbal cues: you see the facial changes, you'll see how they respond... it's how they respond back... just feeling a bit awkward... look away from you(P4)</p>
--	--

<p>been already chat by, like been told by the doctors what to do then it makes it a lot easier because then it's me just rehashing what they've already been told. So it's how they respond back makes a, it's not a, that's a facilitator of it. Whereas with the barriers it's usually if they're just feeling a bit awkward and they're like look away from you or they're, they really don't feel like it's appropriate to talk about such things because it tends to be taboo with a lot of cultures to be talking about you know having sex and things like that. So also, it's also who else is present. Sometimes who else is present is a facilitator and other times it's not. Then, or you just try and bring it up lightly if you know that the patient's going to be a bit awkward with it because you know what the patient's like then you try and make it a kind of a thing that you're talking about it something as not funny, funny but light heartedly rather than bring a serious subject you know it need to be this way and then you can actually bring the serious points afterwards once they feel comfortable talking about it.</p>	<p>it tends to be taboo with a lot of cultures(P4)</p> <p>Presence of partner: who else is present. Sometimes who else is present is a facilitator and other times it's not(P4)</p> <p>Using humour to facilitate: light heartedly rather than bring a serious subject ... then you can actually bring the serious points afterwards once they feel comfortable talking about it(P4)</p>
---	---

Figure 1 Sample of coding during primary analysis of interview transcripts

After completing this process for approximately half of the transcripts, the author commenced a secondary analysis whereby the key phrases identified during primary analysis, were copied into NVivo software (version 9) to assist with coding. NVivo is a qualitative analysis tool that assists researchers in the organisation of coding data. In this case, phrases from interview transcripts were allocated to one or more codes, or “nodes” as they are named in NVivo. Once all the key phrases were allocated, similar nodes were clustered together in categories and descriptive wording was applied to each category. Categories and their descriptions were then copied back to Microsoft Word and were displayed in a table, accompanied by two or three relevant quotes from the transcripts (see Figure 2).

Icebreaker	Physical tools (such as a brochure, assessment tool, check list) that assists the nurse to initiate the conversation.	the leaflet that was introduced within the last year on our ward... that's your ice breaker right there... gives them permission to talk about it... validates the need for the conversation (P1) a prompt tool helps then for patients to raise it and it allows them to tick that box... they might not know that it's actually ok to ask about this at that point in time (P16)
Initiating discussion	How to begin the conversation	I find it easier when the patient asks first(P5) Some women have brought it up themselves and so have just answered the questions as best I can. I don't necessarily go straight in and ask them about their sexuality or what their expectations are (P10) I think sometimes they're actually really quite relieved that someone brings it up (P11) It's the actual words for the first sentence to open the conversation (P17)
Normalising, incorporating into clinical care	Using strategies to normalise psychosexual issues for the patient. Incorporating the conversation into other aspects of care.	it's just part of the natural conversation... that's really important ... to make it part of a natural conversation not something sort of bizarre or weird (P6) If it's in the care plan, perfect, that makes it everyone's business... look this is on your care plan, actually we talk about this to all women... So normalising it (P12) You can do it as a part of a check... There's so many nice gentle ways of bringing it up (P11)
Presence of partner or significant others	Issues around discussing psychosexual care when others are present.	Privacy...they've not got a partner there... people are more likely to be honest if they, you know they don't want to offend their partner... So getting that one on one time is probably the most crucial thing really (P1) who else is present. Sometimes who else is present is a facilitator and other times it's not(P4)

Figure 2 Sample of categories, their descriptions and accompanying quotes

Each transcript was initially analysed independently by at least two members of the research team. The team consisted of the author and her two supervisors. One supervisor is a Professor and has extensive previous experience in qualitative research. The other is a registered nurse with a Masters postgraduate degree and was the nurse who conducted the interviews. Once analysed, the team members then met to share and discuss their findings and tentative themes and subthemes until there was a consensus. If there were any discrepancies the team referred back to the original transcript data.

During this process of coding and defining categories, distinction between groups of these categories became increasingly clear and appeared to demonstrate a logical way to describe them. Data relevant to the code appeared to describe various elements affecting the psychosexual care interaction. These

included the interaction itself (i.e. the conversation), the nurse involved, the patient involved, the health system in which they both were present and less commonly, but still relevant, the society in which they existed. These elements formed the basis of the development of themes used to describe them. All of the categories previously described, fitted into the descriptions of one of these five themes.

Trustworthiness

Qualitative researchers are often criticised for not providing enough information about the strategies used to ensure the trustworthiness of their conclusions (Colorafi & Evans, 2016). Five standards for assessing the trustworthiness of naturalistic inquiries are typically used for this process: objectivity, dependability, credibility, transferability and application (Guba, 1981; Colorafi & Evans, 2016).

Objectivity is the ability of the researcher to remain neutral and as free from bias as possible during the investigation. Colorafi and Evans (2016) describe that objectivity can be addressed by outlining the study's procedures in detail, presenting all the processes of data collection and analysis, reporting the researcher's experience and potential bias and retaining data appropriately for future evaluation. All of these elements have been addressed within this chapter.

Dependability refers to activities of reliability and consistency in procedures (Colorafi & Evans, 2016; Schneider et al., 2016). As described in "Data Collection" above, a semi-structured interview guide outlining the questions and order in which they were raised with the participants ensured that consistency occurred across all interviews. The same interviewer, who was not known clinically by the nurses to address potential bias, conducted all interviews with participants. Data analysis occurred simultaneously alongside data collection to allow for revisions if needed. The roles of the investigator and interviewer are also described in detail under "The Author as a Methodological Instrument" and "Data Collection" above.

Credibility may be assessed by validating the truth of the data (Colorafi & Evans, 2016). In this investigation, investigator triangulation (Streubert & Carpenter, 2011) was implemented by ensuring analytical input of all members of the research team. The team consisted of the author, the interviewer and the supervisor. Each transcript was initially analysed independently by at least two members of the team. The team then met to share and discuss tentative themes and sub-themes. Any discrepancies were referred back to the transcripts and a consensus decision on final themes and sub-themes was made.

Transferability refers to the ability of the findings to be applied in other settings (Colorafi & Evans, 2016). The transferability of this study's findings to other contexts or groups of nurses can be determined by the reader. Strategies were adopted to assist readers in determining the transferability of the findings to other settings such as inclusion of a rich description of the characteristics of the study participants, a description of potential threats to the translation of findings to other contexts detailed under "Participants" above, and finally within the discussion, suggestions for further investigations in other settings. Member checking, a method of establishing credibility of findings through discussions with participants (Polit & Beck, 2014), was also conducted where the nurse who conducted the interviews contacted two of the research participants to discuss the preliminary findings and asked the participants to comment on whether they agreed or disagreed. Both participants agreed that the findings presented were a true reflection of their perceptions on the study topic.

Application is described by Miles and Huberman (2014) and relates to knowing that the findings have the capacity to make changes to the participants and their consumers. Colorafi and Evans (2016) suggest that dissemination of qualitative descriptive findings is one way to address application. The author has sought to address this through dissemination of the study's findings in a variety of ways including professional development study days, presentation of findings at a national nursing conference and dissemination of findings in an international nursing journal. Informal feedback was sought and gained from a number of audience members after the presentations. Gynaecology nurses

working in similar contexts agreed that the findings presented resonated with their experiences working in their practice setting.

By addressing these five standards, the author has sought to demonstrate rigorous assessment of the legitimacy and trustworthiness of the investigation's conclusions.

Ethical Considerations

Ethical approval was sought and granted from the Human Research Ethics Committees of the health institution (approval number 2015149QK) and the affiliated university (approval number SONM44-2014).

The Australian National Health and Medical Research Council (2007 (Updated May 2015)) outline the principles for various elements of the research process including, but not limited to, recruitment of participants, seeking consent, offering the option to withdraw, storage of interview and identifiable data, and maintaining research merit and integrity. All data collection and analytical processes conducted during this investigation adhered to these principles. Interview recordings and transcripts were saved onto a password protected drive with access granted only to members of the research team. Interview transcripts were de-identified after initial transcription and no identifying information has been included during dissemination of the investigation's findings. Written materials will be stored in a locked filing cabinet and digital data will remain securely stored for a period of no less than seven years.

Summary

By exploring a variety of research paradigms and methods, the author was able to appraise and select qualitative description as the most appropriate research design to achieve the aims of this investigation. The setting and the participants for this study were described in order to set the scene for the forthcoming findings. A detailed explanation was provided on the process of conducting interviews with participants and how the analysis of interview transcripts was conducted. Details of these strategies are presented to ensure the

trustworthiness of conclusions made in relation to the findings provided in the next chapter.

CHAPTER FOUR: FINDINGS

Introduction

In this chapter the author will present findings that emerged from analysing interview transcripts of 17 Western Australian nurses working with women undergoing gynaecological cancer treatment. The aim of the study was to gain insight into how Western Australian nurses conceptualise the provision of psychosexual care for women undergoing gynaecological cancer treatment, and to identify what they perceive to be facilitators and barriers to this care. Five themes were extracted during the data analysis with nine corresponding subthemes. The first theme 'Nurses use strategies to aid the conversation' incorporated two subthemes 'Supporting the woman' and 'Facilitating engagement'. A second theme labelled 'Women have unique psychosexual needs' included two subthemes 'Diversity' and 'Receptiveness'. The third theme 'Nurses are influenced by personal and professional experience and values' incorporated three subthemes: 'Confidence', 'Values' and 'Making assumptions'. 'Systems within the health service affect care' was the fourth theme with two subthemes 'Being supported by the system' and 'Working as a team'. The final theme 'Society influences attitudes around sexuality' was a stand-alone theme. Nurses shared examples of how the themes and subthemes could impact care provided in both a positive and negative manner.

To support the themes and subthemes, direct quotes are provided within the text in italics and a coding system (P1 to P17) for each nurse is included. Three dots "..." are shown where superfluous words have been removed from the quotes. A profile of the participant nurses who were interviewed will be presented followed by detailed description of the themes and subthemes.

Participants Profile

Seventeen female nurses participated in interviews to share their perceptions of providing psychosexual care for women undergoing gynaecological cancer treatment. Demographic data was collected around the participant's current

nursing position, years of nursing experience as well as clinical experience within gynaecology, and whether they had completed any education around psychosexual nursing care in the previous three years. A summary is provided in Table 7.

Ten nurses worked in the postoperative gynaecology ward and seven in outpatient clinics. Five nurses worked in a registered nurse role, six in a clinical nurse role and six in specialist nursing roles. The mean years of nursing experience was 23 years (ranging 2 to 40 years) and years of gynaecology nursing experience was 9.7 years (ranging 1 to 30 years). The characteristics of nurses between nursing positions held, number of years nursing experience and number of years gynaecological nursing experience was evenly distributed, although only two nurses had over 20 years gynaecology nursing experience.

Thirteen participants had attended training in psychosexual nursing care within the past three years, three did not attend and one was unsure. Participants were not asked to disclose what training they had attended, however it is known that a link to the online resource on psychosexual care developed by Cancer Australia in 2010 is available on the hospital's education website. This online resource had also been used to implement workshops and study days at the study hospital in the three years prior to commencement of data collection.

Table 7

Participants' demographic data (n=17)

Variable	n
Nursing position	
Registered nurse	5
Clinical nurse	6
Senior registered nurse	6
Number of years nursing experience	
0-9 years	4
10-19 years	2

20-29 years	5
30+ years	6
Number of years gynaecology nursing experience	
0-9 years	8
10-19 years	7
20+ years	2
Participation in education on psychosexual nursing care in the past 3 years	
Yes	13
No	3
Unsure	1

Summary of Themes and Subthemes

The analysis of interviews revealed five themes and nine subthemes identifying the perceptions of nurses on their provision of psychosexual care for women with gynaecological cancer. The first theme 'Nurses use strategies to aid the conversation' related to the verbal interaction, or conversation, that occurred between nurses and women in order to provide psychosexual care. This theme incorporated two subthemes 'Supporting the woman' and 'Facilitating engagement'. A second theme 'Women have unique psychosexual needs' outlined factors that were unique to the individual woman and how they influenced the way the nurse would discuss psychosexual care. These factors were described under two subthemes 'Diversity' and 'Receptiveness'. The third theme 'Nurses are influenced by personal and professional experience and values' outlined how their personal and professional characteristics influenced the care they provided. Theme three included three subthemes: 'Confidence', 'Values' and 'Making assumptions'. The fourth theme was 'Systems within the health service affect care' and described a variety of factors relating to the health system that influenced if and how the nurses discussed psychosexual issues. This theme included two subthemes 'Being supported by the system' and 'Working as a team'. The final theme 'Society influences attitudes around

sexuality' was a stand-alone theme and related to the influence of societal factors on the provision of psychosexual care.

Each of the themes and corresponding subthemes is presented in Table 8 with a description of each.

Table 8 Summary of theme and subtheme descriptions

Theme	Subtheme	Description
Nurses use strategies to aid the conversation	Supporting the Woman	Nurses support women by adopting strategies to pursue a conversation about psychosexual issues.
	Facilitating Engagement	Nurses described strategies they used to promote engagement with women in facilitating the conversation.
Women have unique psychosexual needs	Diversity	Nurses describe diverse characteristics of the women they care for which can influence the provision of psychosexual care.
	Receptiveness	Women differ in their receptiveness to a conversation about psychosexual issues and this can affect nurses' care around psychosexual needs.
Nurses are influenced by personal and professional experience and values	Confidence	Nurses' confidence around the provision of psychosexual care differs and can influence their care.
	Values	Nurses describe professional and personal values that may influence their clinical practice.
	Making assumptions	Nurses reveal assumptions around the provision of psychosexual care.
Systems within the health service affect care	Being supported by the system	Established systems in the health service can influence the capacity of nurses to provide psychosexual care.
	Working as a team	Nurses share perceptions of working in a cancer care team related to psychosexual care provision.
Society influences attitudes around sexuality		Nurses describe the influence of societal factors on provision of psychosexual care.

Theme 1: Nurses use strategies to aid the conversation

The verbal interaction, or conversation, that occurred in order to provide psychosexual care was a common point of discussion amongst all nurses during the interviews. When pursuing a conversation related to psychosexual care, nurses described what they felt impacted their verbal interaction with women and the strategies they used to aid the conversation. Strategies ranged from communication techniques both verbal and non-verbal, the use of clinical resources and employing professional behaviours instilled in the philosophy of nursing such as advocacy, informed consent and confidentiality. These strategies were captured under two subthemes, 'Supporting the Woman' and 'Facilitating Engagement'.

Subtheme: Supporting the woman

In order to provide support to women while undertaking a discussion about psychosexual issues, nurses described adopting a variety of strategies to assist them. Many of these related to communication strategies, including the choice of words, what to say and when to say it. They considered it important to individualise care by adapting their approach based on the individual characteristics, needs and response of the patient. One nurse suggested: *"I think every case is different"* (P10). Another nurse echoed this by sharing: *"You have to be guided by the patient...it's a real individual assessment"* (P6).

Nurses discussed providing women with the choice to pursue the conversation or not, legitimising their concerns, and giving them permission and reassurance that it is acceptable to discuss psychosexual issues. For example, one nurse shared: *"I would start by saying have you thought about things like that and the patient would either say yes or no... would you be happy to have a conversation about it"* (P5). Another nurse's comments concurred with this strategy as she noted how: *"sometimes people just need to have that opportunity to open up... giving them permission"* (P13).

When recalling scenarios of providing psychosexual care, nurses described the act of purely supporting and listening therapeutically to the woman's story. One nurse revealed how she incorporated this strategy into her care: *"It was just really listening to her... this was probably the first opportunity that she'd actually spoken to someone ... it didn't seem like it was a problem that she was allowed to have"* (P1). Another nurse reiterated how the listening could enable the woman to be reassured that her feelings were acknowledged and validated: *"they just want to know that it's ok to feel that way"* (P12).

Examples were offered during the interviews where nurses also supported the woman by advocating for her psychosexual needs. This advocacy could include strategies to encourage the woman to discuss identified issues with other members of the health care team. The following quote illustrates one nurse's experience of prompting a patient to consider questions in advance of a follow-up appointment: *"I would say to the patient later did you have any questions about the sexual function after this surgery that you'd like to talk to the doctors about... I would encourage her to talk to them at her outpatient appointment"* (P8). Another scenario was provided where challenges arose for a woman for whom English was not her first language. This nurse described the woman's concern around protecting her desire for confidentiality and anonymity: *"They're worried that this interpreter will talk within their community"* (P15).

Subtheme: Facilitating engagement

The second subtheme under "nurses use strategies to aid the conversation" addressed the strategies nurses used to promote engagement with women to facilitate the discussion. A key strategy identified by most of the nurses was establishing rapport with the woman; that is, a trusting, therapeutic relationship. Once established, this rapport was seen as an important strategy to promote a level of comfort when discussing intimate issues. To illustrate this strategy, one nurse described how: *"I obviously see how they interact with me ... get them comfortable with me... If they feel uncomfortable with me to start with and close up then I leave it until a bit later... we get a rapport together"* (P3). The

word 'trust' was often used synonymously with rapport when nurses discussed the importance of establishing a relationship with women. Reflecting on the importance of trust when discussing psychosexual issues, this nurse explained: *"you have to gain their trust. They have to feel comfortable that if they're going to open up and say stuff that you're going to be cool about it...that they're going to feel safe...getting them to feel that they can trust you"* (P17). Conversely, where establishing rapport was met with difficulty or was not formed, this was seen as a barrier to discussing psychosexual issues. Another nurse clarified the challenges she encountered: *"Whether I'm able to make that connection with that person....if there was someone that I could feel we weren't relating, connecting well then I would probably, I think that could be quite a barrier"* (P14). A colleague also provided an example of the importance of establishing a relationship to be able to facilitate engagement: *"I would rarely have this conversation with a patient if I didn't have a relationship with her"* (P6).

Establishing rapport was recognised to be influenced by other system related factors such as short length of stay or lack of continuity of care. The following quote reflects one nurse's experience of how the length of a patient's hospital stay affected her ability to develop rapport: *"Some people only stay a very short time, those who stay longer that you develop a relationship with it's easier to talk to them"* (P8). Another participant shared a similar scenario around the challenges associated with developing rapport with patients but this time it related to her own roster and the length of time spent with the patient: *"I think it's difficult that when you get a rapport with somebody and then you're off for a few days...then you can't follow it through...I feel like I've abandoned them...continuity of care is the important thing"* (P3).

Some nurses interviewed highlighted examples of when initiating the conversation could be challenging. *"It's the actual words for the first sentence to open the conversation"* (P17). They described strategies they used to assist them to engage with the women. Some nurses liked the use of a prompt or tool such as a brochure or patient-completed assessment as explained by this nurse: *"The leaflet that was introduced within the last year on our ward... that's your ice*

breaker right there... gives them permission to talk about it... validates the need for the conversation" (P1).

Knowing what to say was a concept that nurses considered important when engaging in a conversation about psychosexual care with women. They described that knowing what words to use could be challenging. *"It's not that scary...people are open to the question... I think for most people it's the words."* (P17). Another nurse expressed a similar sentiment: *"It's definitely knowing the right things to say and when to say it."* (P13). Some nurses described using communication models such as the PLISSIT model (Annon, 1976) or that having a script or communication guide would be a helpful strategy to facilitate knowing what to say. For example, this nurse suggested: *"Using the PLISSIT model as well for nurses"* (P12), and a colleague recommended: *"maybe have a script"* (P8). Another nurse disagreed with the idea of using a script, saying: *"You cannot have a set thing that you're going to say to every person because it doesn't work out like that"* (P10). One nurse suggested that asking more experienced colleagues to assist in teaching them what to say could help them overcome this barrier: *"I would find a colleague who does it well and I would ask them can I, can you teach me what to say, can you teach me what not to say"* (P5).

Nurses described that normalising the conversation helped them to create comfort around the conversation, for both themselves and the women. When considering how this nurse approached the discussion, she explained: *"It's just part of the natural conversation... that's really important ... to make it part of a natural conversation not something sort of bizarre or weird"* (P6). They described ways in which they incorporated it into other parts of their clinical care, for example: *"You can do it as a part of a check... There's so many nice gentle ways of bringing it up"* (P11). Another nurse suggested that having documentation could assist them in explaining to women that the care is provided to everyone and would help in making them feel more comfortable: *"if it's in the care plan, that makes it everyone's business...look this is on your care plan, actually we talk about this to all women...so normalising it"* (P12).

Having privacy was also identified as important in fostering a conversation around psychosexual issues. Some nurses felt it was important to also have the patient on their own, with no partner or significant others present. One nurse described a helpful strategy as: *“having a very quiet personal space to be able to talk to them and being open... making sure that we’re not going to get interrupted which is probably the biggest thing”* (P15). On the matter of having others present, another nurse related that *“sometimes who else is present is a facilitator and other times it’s not”* (P4).

Other considerations around facilitating engagement included timing, *“you’ve got to pick your times”* (P11) and the use of humour, *“Light humour’s usually of advantage but again sometimes it can be really inappropriate”* (P6). A number of nurses echoed the sentiment that following the patient’s lead was a preference, *“I find it easier when the patient asks first”* (P5).

Theme 2: Women have unique psychosexual needs

The second theme “Women have unique psychosexual needs” outlined factors that were unique to the individual woman and how they influenced the way the nurse would discuss psychosexual care. These factors were described under two subthemes, “Diversity” and “Receptiveness”.

Subtheme: Diversity

Nurses described that it was challenging to discuss psychosexual issues with women who were culturally diverse from themselves, in particular Indigenous women and Muslim women. When recalling scenarios of discussing psychosexual issues with culturally diverse women, this nurse revealed: *“There are certain cultures where I, you know might not feel as confident to broach the subject... because I don’t have necessarily the same understanding of their culture as within the western world”* (P13). One nurse recalled feeling uncomfortable about knowing what was appropriate to discuss and was fearful of offending or embarrassing the woman. *“The different cultures, what if I say something that’s*

going to embarrass them, what if it's not appropriate... in case you do offend the patient I suppose and that's the probably mainly the biggest fear" (P12).

Nurses shared additional challenges when they faced discussing psychosexual issues with women who had limited or no English language skills, and the fact that using interpreters was often not helpful. One nurse explained it *"can be difficult to ask those kind of intimate questions via an interpreter... so I think there are a whole group of women that probably miss out a little bit... I think it's probably something we probably don't do too well" (P13).* The issue of confidentiality was highlighted as a challenge in using interpreters as articulated by one participant: *"Ninety percent of them probably won't talk through an interpreter because it's using a third person to talk about something that's extremely intimate...they're worried the interpreter will talk about them" (P15).*

Nurses described the range of sexual diversity they encountered amongst the women they cared for. One nurse clarified the sexual diversity as: *"Some of them are virgins, some might be lesbians, some might have never had sex with anyone" (P2).* This diversity was acknowledged as a challenge for some of the nurses interviewed in this study. *"Sexuality is so diverse now maybe that might hold them (nurses) back to really wanting to explore it further" (P12).* For other nurses, facing women who were sexually diverse from themselves was not an issue. *"Gay people... I just treat them as if they're the same as anybody else 'cause they are... we'd be very foolish to miss the conversation because somebody's gay because you would be just failing to acknowledge their sexuality" (P6).* One participant highlighted how she personally felt it took some time and experience to gain confidence in discussing sexuality with homosexual women: *"Same sex couples... it was a little bit different just I think confidence-wise for me originally... identifying what issues there were" (P17).*

Nurses identified they would familiarise themselves with the woman's sexual history from her medical record and how this information would influence their approach to the discussion. Examples included knowing and being sensitive to

women who had a history of sexual violence: *“where they’ve been (in) a sexual assault or some issues like with where they’ve had sex problems prior”* (P3), or awareness of information around relationship status such as *“whether they’re married or single or in a de facto or widowed... usually you can see by the next of kin or even same sex partnerships”* (P10).

Subtheme: Receptiveness

The nurses described assessing the women’s response to their initiating a discussion around psychosexual issues, using both verbal and non-verbal cues. They outlined how they would evaluate how receptive they thought the woman was to have the conversation. One participant explained that *“it’s definitely knowing the right things to say and when to say it and it’s also being able to pick up on cues ...you can read between the lines”* (P13). The importance of interpreting non-verbal cues was noted by another nurse: *“You see the facial changes, you’ll see how they respond...it’s how they respond back...just feeling a bit awkward...look away from you”* (P4).

This assessment of the woman’s receptiveness would then affect how nurses would pursue the discussion. Some nurses felt that all women feel uncomfortable discussing psychosexual issues, *“women they won’t ever be comfortable talking about... their relations”* (P11), and, as another suggested, *“there’s a definite discomfort... it’s definitely something that people are not comfortable with talking about... I think it’s across the board”* (P13). However, there were others who felt that once the topic was raised most women were willing to engage in the conversation: *“I’m always surprised at usually how comfortable women are to talk about it and perhaps that’s an indication of their need”* (P14).

Nurses identified that they found it helpful when the patient was comfortable with pursuing a conversation about psychosexual care. A nurse illustrated this point, recounting: *“When I know that the patient is comfortable... I find it a lot easier and it makes me more comfortable to talk to them about it”* (P5). Another nurse agreed, recalling a scenario where the patient displayed comfort: *“She was*

comfortable in her sexuality and speaking about it openly, I was happy to talk about it and if I couldn't answer any questions I referred her on" (P3).

Theme 3: Nurses are influenced by personal and professional experience and values

Nurses acknowledged they are individuals who possess a variety of personal and professional characteristics which manifest in the care they provide. From the interviews, nurses reveal these factors can influence care both positively and negatively. Three subthemes encompass this theme, "Confidence", "Values", and "Making Assumptions".

Subtheme: Confidence

Nurses in our study were able to describe their level of confidence when discussing psychosexual issues with their patients. A range of confidence levels were described from *"there is some confidence depending on who I'm speaking to" (P4)* and, *"I'm not a hundred percent confident in talking about it" (P5)*, to *"I'm quite confident, I don't mind at all" (P13).*

The Western Australian nurses identified how their level of confidence was affected by a variety of factors. For example, many nurses recognised how their substantial gynaecological clinical nursing experience positively affected their confidence. *"I think it's something with experience... it can be taught but it takes time" (P13).* Another nurse reflected a similar feeling: *"I developed my confidence through experience" (P17).*

The age of the women they were speaking to was acknowledged as influencing how comfortable the nurses felt with the conversation around psychosexual care. One nurse admitted: *"I'm not always comfortable depending on their age" (P8).* Similarly, the age of the nurse was also identified as a contributing factor towards the level of confidence they felt. To illustrate, a number of nurses who were older described having more confidence to engage in a discussion with their patients. One nurse reflected on how her confidence has grown with age: *"As I've got older...that shyness or embarrassment has gone... I've become more*

confident I suppose” (P14). In contrast, a younger nurse shared: “I don’t feel confident to ask these questions and I think that there needs to be a lot more education in the system for younger nurses who aren’t comfortable or confident” (P5).

A number of nurses recounted having participated in relevant education, such as the professional development study day on the psychosexual care of women with gynaecological cancer or having accessed the Cancer Australia (2010) online resource “The Psychosexual Care of Women Affected by Gynaecological Cancers”. They acknowledged the positive influence this experience had on their confidence and practice. This nurse recalled the value she gained from attending one of the professional development study days she attended at the hospital: *“I felt that the study day I went on was so useful because that was just full of scenarios and obviously you’re there with your peers talking about it together...I found that immensely helpful” (P1).*

Others who may not have attended recent professional development sessions around the psychosexual care of women with gynaecological cancer, identified that they did not feel knowledgeable and this affected their confidence. One nurse shared her concerns as: *“We shouldn’t be expected to just kind of dash in there and start talking about sex when we really haven’t got the knowledge” (P2).* They identified educational needs which, if addressed, would assist them to overcome their knowledge deficits and improve their confidence. The desire for further education was reinforced by this participant who stated: *“I feel I need to know more information on, need to know more ways of approaching it rather than getting scared and then kind of backing off” (P4).*

Having all the answers was a concept acknowledged as noteworthy by many nurses as they felt unprepared to address women’s concerns and questions and this affected their confidence. To illustrate, one nurse shared how: *“I don’t want them to open up a box that I’m going to go, oh I don’t have a clue what to do from here” (P17).* One nurse rationalised the thoughts of her colleagues *“Talking to other nurses they say oh I don’t know enough about it.” (P8).* Alternatively, some

articulated it was not necessary to have all the answers in order to discuss psychosexual issues. *"You don't have to fix it...I don't have all the answers and I am always learning...it's ok not to have the answers"* (P12).

The level of comfort nurses felt when discussing psychosexual issues often related to what the women revealed during the conversation. When women shared intimate details of their sexual activities or asked questions and advice about activities, this caused some nurses to feel uncomfortable. One nurse recalled a scenario where a patient asked her about resuming anal sex with her partner. The nurse described feeling unprepared for the question and this contributed to her discomfort, *"I felt uncomfortable and wasn't ready for that question... I guess it's just something that I wasn't ready to hear"* (P5).

Nurses elaborated on how experiencing the emotion of fear was associated with discussing psychosexual issues. One nurse declared: *"The word sex scares people"* (P1). Another nurse provided a hypothetical example of the fear experienced by her colleagues when discussing psychosexual issues: *"They are scared that they're going to ask a question and the person's going to come back with something, then they're going to go urgh, I'm up shit creek..."* (P17).

Subtheme: Values

Nurses described a range of both professional and personal values which influenced their practice of providing psychosexual care to women receiving gynaecological cancer treatment. Some nurses highlighted the value they placed on the topic of psychosexual care. For example, one nurse shared: *"This is an important topic to me, sexual health is really important"* (P3). Many participants felt discussing psychosexual care was important and that they had a sense of professional responsibility to discuss issues of sexuality with the women they were caring for. *"Why wouldn't we talk about something as important as this?"* (P16). Another nurse reiterated how providing psychosexual care was the role of the nurse: *"I just feel it's part of our job, it's part of our responsibility...it's a need that's often not met so you just have to do it and have the knowledge to do it"* (P6).

Some nurses shared scenarios where the consequence of not discussing psychosexual issues had a negative consequence for the woman and how this influenced their future practice. Reflecting back on a particular patient and her experience was captured in this nurse's story: *"I always remember her because that was quite a moving one... made me realise why you need to ask the questions... you might be the only person that they feel they can talk about it with"* (P1). One nurse demonstrated how she acted upon this important role when she discussed how she mentors junior nurses who may be reluctant to address psychosexual issues. She explained: *"I would just try to impress upon them that there are big consequences if they don't (ask)... a minute's worth of feeling a little bit embarrassed could save a patient you know a whole lot of problems... There's so many things that just compound that problem if you don't ask"* (P11).

The personal beliefs and self-awareness of nurses around the topic of sexuality were identified as factors that influenced their practice. One nurse described the value she places on the *"awareness of where your sense of self and your own awareness of your own sexuality fits in... your own cultural beliefs, your own influencing factors... if you're awkward in talking about sex normally then you're going to feel maybe awkward talking about it to a stranger"* (P12). Another nurse reflected that values instilled on her at an early age influences her current practice: *"I mean my own childhood experience was you never talked about sex so that overflows into this because I think oh no, no, no I can't talk to her about it"* (P8). One participant recalled a scenario where another nurse revealed her reasons for not discussing psychosexual care with women: *"I have overheard one person say that they wouldn't initiate that conversation because their sex life is private so why would they ask anyone about theirs"* (P1).

Many nurses also discussed the influence of both the age of the woman, and the age of the nurse, on their ability to engage in a discussion around psychosexual issues. Some nurses felt that a discrepancy in the age between an older woman and a younger nurse was a barrier: *"if you're 21 you're talking who's you know 60 it's like talking to your mam [mother] or your grandma about stuff and that's difficult"* (P6). Another nurse however, felt her younger age made it more

acceptable to discuss psychosexual issues: *"I think because the perception that maybe it's more appropriate to talk with someone younger or they won't be as embarrassed because they assume that everyone talks about it all the time anyway"* (P1).

Subtheme: Making assumptions

The interviews with the nurses revealed that a wide variety of assumptions were made either by themselves or their colleagues in relation to the women when discussing psychosexual issues. Examples of the types of assumptions made related to whether or not a discussion regarding psychosexual issues would be relevant to the woman, and were based on factors such as age, relationship status, health status or a 'gut' feeling. Some nurses observed that they made assumptions and were able to articulate the assumptions made by themselves or their colleagues. This nurse provided examples of the types of assumptions that can be made and reflected that she has made assumptions herself: *"Making assumptions that people don't have an active sex life or if someone's single then therefore it's not an issue for them or if someone's a certain age that they won't be thinking about it... maybe I did have assumptions and put people in categories so I try to not do that"* (P1). Another nurse shared examples of assumptions made by her colleagues: *"They make an assumption that someone's not sexually active based on... singleness or age"* (P11). This sentiment was echoed by another nurse who stated: *"They think that 70 pluses don't have sex"* (P6).

Some nurses articulated that their own bias is created based on past personal or professional experience and that this bias influenced their care. One nurse suggested: *"What we think is right for us must be right for the other people... we don't consciously do that but it comes across"* (P12). Another nurse shared her experience of making inaccurate assumptions and that she learned: *"After that I was like... you shouldn't make assumptions about people"* (P13).

Other nurses did not acknowledge that they made assumptions but during the interviews they described various assumptions that they made whilst caring for

women. Assumptions about if and how to discuss psychosexual issues were made in relation to patient factors such as age, appearance, health status or their own instinct. Age was a common factor around which assumptions were made. For example, this nurse declared her assumptions about whether women wanted to discuss psychosexual care: *"It's usually the last thing on their mind ...unless they're extremely young"* (P3). Another nurse shared her thoughts on which of the women she provided care to should receive psychosexual care: *"Especially for the younger ones...it's not quite the same for a 70 year old... I think it's more an extreme case where you've got 50 years or 80 years of your sexual life as opposed to perhaps ten good years left that it's going to cause problems in relationships"* (P2). One nurse provided a scenario where her assumption around age and sexuality was challenged: *"An older woman who was in her late seventies that asked me when she could have sex again... people that you think would don't and people that you think won't will"* (P10).

Assumptions were made by nurses, based on the patient's appearance. One nurse suggested that she makes decisions around whether to initiate a discussion about psychosexual issues based on assumptions related to the woman's physical appearance: *"You can almost probably... pick the patients who you know that their appearance is extremely important to them and who might have an issue about things more... you'd probably be more careful to address the subject with them than with others who you think it's more important for them just to be well"* (P6). Another nurse provided a similar example where she assumed that psychosexual care would be important to this woman: *"She's gorgeous looking and skinny and she's going to lose her hair and she's not going to be able to have babies anymore and you just sort of you know, know that she's going to need a lot of extra help"* (P2).

Nurses also made assumptions around when they felt it was the right time for the patient to discuss psychosexual issues based on the status of their health or where they were in their treatment journey. Most nurses who discussed this assumption felt that discussing issues of sexuality immediately after surgery was not appropriate and that women would not want to have a conversation

about psychosexual care at that time. One nurse professed: *"I don't think when you're tired after post, after surgery that you want to be sitting down reading or having a discussion about sex"* (P10). This assumption was echoed by another nurse who suggested: *"During treatment they don't care, they just want to get this... sorted and that's probably an insignificant part of their care at that stage"* (P15). Another nurse suggested that for most women, survival and coping with side effects was their priority during active treatment and that psychosexual issues would develop later, making the assumption: *"I think you know all you want to do is have your surgery, get your results... have I got a cancer I'm going to die from... if you're going to have chemotherapy that's another whole big round of issues that's, you know it's the hair, it's the vomiting, it's the fatigue, it's all that sort of stuff and again sexuality's probably low on most people's list... it's further down the track that I think most of these arise for most people but I could be wrong"* (P6).

Finally, some nurses expressed assumptions about whether psychosexual care is appropriate for particular women or not based on their own instinct or 'gut' feeling. One nurse illustrated this assumption by suggesting: *"I think I'm fairly sensitive to peoples' character and personality and sometimes I just feel like that person wouldn't appreciate me talking about psychosexual issues"* (P8). Again, the assumption that coping with the treatment phase was the priority for women was made by this nurse suggesting that: *"For the couple their centre is for the treatment for the disease you know and sexually yeah they've put it on their last of the list (sic)"* (P9).

Theme 4: Systems within the health service affect care

The fourth theme, "Systems within the health service affect care", developed from nurses describing a variety of factors relating to the health system that influenced if and how they discussed psychosexual issues with women undergoing gynaecological cancer treatment. These factors are encompassed under two subthemes, "Being supported by the system" and "Working as a team".

Subtheme: Being supported by the system

During the interviews, nurses discussed a range of system related factors that either facilitated or hindered their capacity to discuss psychosexual issues with women. These factors included having appropriate mentorship, procedural factors such as guidelines, documentation and referral pathways, length of stay, continuity of care, competing duties and gender of the treating health professional.

Nurses identified that when mentors were readily available to assist them in answering questions or clarifying information about sexuality, this facilitated their ability to discuss psychosexual issues with women. One nurse suggested that when an issue was raised that she felt was out of her area of expertise, she had more experienced staff to help her, recalling: *"I would go and clarify it with a senior staff member"* (P5). Another nurse identified other members of the multidisciplinary team who were available to provide this assistance: *"I had (name) who's a clinical psychologist so I could run stuff past her"* (P17). An experienced nurse described how she would mentor and provide support to less experienced nurses. *"I'll always encourage the younger staff to... come with me to hear how I talk about it... just listen to the conversation I'm having because this is what you need to learn how to do...and you can only learn by listening and by being involved in the conversation"* (P6).

Most nurses agreed that if a nurse was able to care for a woman on multiple occasions, thereby providing continuity of nursing care, this facilitated their ability to provide psychosexual care. One nurse feels there *"has to be quite a lot of trust... not normally your first meeting... patients that you've looked after you know for a few consecutive days... then they're more open"* (P1). Another nurse articulated that continuity of care was aligned with establishing trust, or rapport, with the women and found it difficult due to the part-time nature of her roster *"Cause I'm only part-time too I don't have that flow on where I thing (sic), I'm nursing someone, exactly the same person for 5 days in a row... so I'm not forming big rapports with people"* (P2).

In some cases, having systems in place were seen by nurses as helpful but in other cases they were identified as a barrier. Referral pathway practices were described whereby women could access specialised care that was beyond the knowledge level of the front-line nurse. This nurse described how the referral system could be used for sexuality issues: *"You need to identify if there is an issue and you will know where to send them for the management of that issue"* (P17). Some nurses felt the ability to refer women on to specialised care was a supportive measure, whereas others felt this practice was an opportunity for some health professionals to pass on the responsibility of psychosexual care rather than to attempt to address it themselves. One participant suggested: *"The referral process as well like because someone thinks it's someone else's responsibility... there's lots of assumptions that someone will pick it up... there's an expectation that if the nurse doesn't talk about it the doctors will talk about it"* (P12).

Some of the nurses identified that the use of appropriate documentation facilitated psychosexual care. This nurse advised: *"It's often led into through with actually the documentation that we have"* (P13). The use of a clinical assessment tool for women with gynaecological cancer was seen as a facilitator for initiating a discussion about psychosexual issues. This nurse explained: *"When the women come in they fill out a form and one of the forms has a list of symptoms they might be experiencing at the moment... so that form they fill out is a perfect lead in... I can actually go through that chart and say oh you've ticked this you know what's happening there"* (P14). However, it was identified that challenges arose when documentation either was not available or was not used and this could result in making an assumption that psychosexual care is being delivered by other members of the team. *"We just assume the doctors will say something... is it documented? No. ... we think they do (discuss psychosexual issues)... documentation is not necessarily followed through either"* (P12).

The nurses who were interviewed felt that when women stayed in hospital for only a short length of time, this was a barrier to providing psychosexual care. One nurse suggested that: *"they're not in hospital very long, you don't often get*

that opportunity" (P10). Another nurse also agreed saying: *"Sometimes they don't stay long enough for you to approach it"* (P8). Also, the gender of the treating health doctor was seen as a factor that could influence the provision of psychosexual care, in that nurses felt women were less likely to discuss psychosexual issues with a male. This nurse explained: *"The fact that most of it, examinations are always done by men... they're not always as comfortable to talk about sexual issues with male doctors... I think they're more likely to open up with female doctors"* (P13). Some nurses described being too busy with other duties to have time to discuss psychosexual issues. One nurse justified her practice by explaining: *"I haven't really had the time I suppose to be talking about psychosexual health"* (P7). Another nurse explained that when women were asked about sexuality, complex issues were sometimes raised and that a lack of time to discuss them was problematic for nurses: *"Time would be a barrier...sometimes you'll ask the question and stuff will come out that you think oh I haven't got time"* (P17).

Subtheme: Working as a team

These Western Australian nurses highlighted that working in a multidisciplinary cancer care team provided the support and referral strategies that were needed to provide appropriate care. Having specialists with an expertise in the area of psychosexual care was seen as a facilitating factor. This nurse explained *"I'm not an expert on sex but that if they have problems that we have a series of people we can refer them to"* (P6). Another nurse suggested that it was helpful to have a specialist to refer to when the care went beyond her level of experience: *"I think she's more expert to deal with that than me... I can offer them kind of limited information and then I like to pass them onto the experts for their input"* (P13).

The nurses did however identify that challenges existed when working as a team. In some cases, they felt that the roles and responsibilities of the cancer team members were not clearly defined and the majority felt that medical professionals in particular did not fulfil their role in psychosexual care. An

example of this sentiment was provided by a nurse who shared: *"I think the doctors don't address that as much as they possibly should, it's extremely clinical when they do because it's all about their treatment"* (P15). Similarly, this nurse felt that: *"not many medical staff will initiate a conversation about sex"* (P8). Additionally, one nurse felt there were expectations placed on them as a nurse to discuss psychosexual issues that were sometimes unable to be fulfilled. *"There's bigger expectations on nurses to perform these things"* (P2).

Theme 5: Society influences attitudes around sexuality

The final theme "Society influences attitudes around sexuality" relates to the influence of societal factors on the provision of psychosexual care. These factors related to community attitudes and knowledge about sexuality and included a lack of consensus around the definition of sexuality, sexuality as an intimate topic and attitudes relating to sexuality and body image.

One nurse considered there is sometimes confusion around identifying the difference between sex and sexuality. She explained: *"The difference between sexuality and actually, and actual sex and I probably don't really differentiate between them a great deal... sexuality is the whole aspect of a woman"* (P6).

By reflecting that *"sex is still really taboo in our society"* (P12), another nurse identified the nature of sexuality as an intimate topic. This statement was provided within the context that differences in attitudes between members of Australian society relate to the acceptability of discussing psychosexual issues and may influence care provided by nurses. Other nurses echoed this sentiment and suggested that the age of the woman and the nurse affected whether it was acceptable to discuss sexuality: *"An old lady...they don't feel like they can talk...sometimes they feel they can't or don't want to speak about it because you just don't do that"* (P3). The nature of sexuality as an intimate topic was described by one nurse who suggested that some women felt it was too private a topic to discuss. However, she identified that this was an assumption, suggesting: *"To some people their sexual activity is very, very private and they don't like to talk about it. That's my assumption... I think younger, younger staff*

like grads and inexperienced staff would have, would be self-conscious, feel self-conscious about approaching a subject that some people feel is private and don't like to talk about it" (P8).

Finally, the nature of gynaecological cancer and its treatment and how this affects body image and femininity was also discussed. In recalling conversations about psychosexual care with women, one nurse clarified: *"I would also talk to them about how they actually see themselves and does it sort of have a big impact on them" (P6).* One nurse described that women with breast cancer are confronted with body image issues more overtly than those with gynaecological cancer due to the fact that the reproductive organs are not seen by others. She reflected: *"There's obviously a physical thing about breast reconstruction and body image... they would get all this information and get to talk about things more... gynae it's internal...so I think we tend to ignore the fact that you know you affect some body image if you've had all your reproductive organs removed and that kind of thing and how you'll feel differently, I don't think we view it as the same because it's not outwardly visible" (P1).*

Conclusion

The five themes and corresponding subthemes that emerged from the analysis of seventeen interviews with Western Australian nurses, provides a descriptive, comprehensive summary of their perceptions, as is the goal of qualitative descriptive research. The nurses described commonalities in the factors that influenced psychosexual care of women with gynaecological cancer however sometimes their views differed as to whether they had a positive or negative effect on care provision.

The findings from this study reflect the views of seventeen Western Australian gynaecological cancer nurses, a cohort for which perceptions on the psychosexual care of women with gynaecological cancer had not previously been investigated. The findings reflect a unique group of nurses who are influenced by the sociocultural environment in which they live and work. A

discussion around a variety of issues that emerged and how these compare and contrast to findings in international settings will follow in the next chapter.

CHAPTER FIVE: DISCUSSION, RECOMMENDATIONS AND CONCLUSION

Introduction

In this chapter the author will discuss the findings that emerged from analysing interview data which provided insight into how Western Australian nurses conceptualise the provision of psychosexual care for women undergoing gynaecological cancer treatment. The purpose of the discussion will be to present the findings of this investigation within the context of the current literature, to explore how they compare and contrast with what is already known and to provide recommendations for clinical practice, education and further research.

Brief Overview of Findings

The interview data analysed from this investigation revealed five themes and nine subthemes. The first theme 'Nurses use strategies to aid the conversation' incorporated two subthemes: 'Supporting the woman' and 'Facilitating engagement'. This theme described how nurses pursue a conversation with women about psychosexual care and how they support and engage with women during this dialogue. The second theme revealed that 'Women have unique psychosexual needs' and included two subthemes: 'Diversity', and 'Receptiveness'. Within this theme nurses explained how women differ in relation to their psychosexual needs by describing their diverse characteristics and the way they differ in their receptiveness to a conversation about psychosexual needs. Theme three informed that 'Nurses are influenced by personal and professional experience and values' and included three subthemes: 'Confidence', 'Values', and 'Making assumptions'. Nurses described how their confidence levels in discussing psychosexual issues and their professional and personal values influenced their care. They also explored assumptions they made about psychosexual care. The fourth theme 'Systems within the health service affect care' comprised two subthemes: 'Being supported by the system' and 'Working as a team'. In this theme nurses discussed the influence of health care systems and how working within a cancer

care team influenced their provision of psychosexual care. Finally, theme five 'Society influences attitudes around sexuality' described how societal factors influenced the provision of psychosexual care.

Comparison with Existing Literature

While a variety of international studies (Ayaz, 2013; Ferreira et al., 2015; Fitch, et al., 2013; Gilbert et al., 2016; Julien et al., 2010; Magnan et al., 2005; Magnan & Reynolds, 2006; Olsson et al., 2012; Park et al., 2009; Saunamäki et al., 2010; Sporn et al., 2015; Stead et al., 2003; Tsai, 2004; Vermeer et al., 2015; Zeng et al., 2012) have previously explored factors influencing communication of health professionals on the topic of psychosexual care, this investigation was the first of its kind conducted with gynaecological nurses in Australia. It was topical given the instigation of the Cancer Australia online resource (2010) and the potential influence this resource may have had on nurses working within gynaecological cancer care. While it is not possible to directly link the Cancer Australia resource with the participants' responses, it was important to describe the perceptions of these Western Australian nurses in order to compare and contrast the findings with international settings, and to reveal what similarities and differences exist in this population.

Overall, the results of this Western Australian study resonate with the experiences of international cancer care health professionals in countries such as The Netherlands, Sweden and Canada (Fitch et al., 2013; Olsson et al., 2012; Vermeer et al., 2015). The importance of developing rapport between the professional and patient, the intimate nature of the subject, the personal inhibitions that influence the delivery of care, the making of assumptions and having a sense of responsibility are all identified as contributing factors. The value of this shared experience offers the potential to develop tools and strategies to improve care which could potentially translate across a variety of global settings.

The first part of this discussion will focus around three of these concepts embedded within the themes and were chosen for their capacity to challenge

nurses to reflect on their own practice and care setting to make improvements in clinical practice. The concepts to be discussed include: the influence of rapport; assumptions nurses made about the women; and the lack of clarity around expectations on nurses to discuss psychosexual issues.

Next a summary of recommendations will be provided to offer suggestions for improving clinical practice in the area of gynaecological cancer care, education opportunities to improve the quality of psychosexual care provided to these women and ideas for further research in this area. Finally, a conclusion for this thesis will be presented.

The influence of rapport

Women diagnosed with gynaecological cancer are at risk of suffering significant psychosexual effects as a result of their disease and treatment (Cancer Australia, 2016). As discussed earlier in the literature review, there is a wealth of evidence to support the notion that women wish to discuss sexual health issues with health care professionals including nurses (Bal et al., 2013; Ekwall et al., 2003; Hordern & Street, 2007a; Lara et al., 2012; Rasmusson & Thome, 2008; Sporn et al., 2015; Stead et al., 2003; Vermeer et al., 2015; Wilmoth et al., 2011). Despite this expectation around care needs, it is known that nurses and other health professionals are not meeting the needs of women when it comes to discussions around psychosexual care (Ayaz, 2013; Ferreira et al., 2015; Gilbert et al., 2016; Park et al., 2009; Saunamäki et al., 2010; Sporn et al., 2015; Stead et al., 2003).

The reasons for the gap in care provision are complex and diverse however the literature identifies that similarities exist within international settings around the barriers and facilitators that contribute to the practice of psychosexual care. Barriers affecting psychosexual communication between the nurse and the women were common and included issues such as nurses feeling uncomfortable or embarrassed to be pursuing a conversation about sexual health, a mismatch in expectations between the woman and the nurse around the woman's desire for discussing psychosexual issues and that it was a low priority for women, and

a lack of educational preparation and knowledge around how to carry out a conversation relating to psychosexual care (Ferreira et al., 2015; Fitch et al., 2013; Hordern & Street, 2007a; Julien et al., 2010; Olsson et al., 2012; Saunamäki et al., 2010; Stead et al., 2003; Tsai, 2004; Vermeer et al., 2015; Zeng et al., 2012). The nurses interviewed for this study also reflected these views as identified in the theme “Nurses are influenced by personal and professional experience and values”. In the subtheme “Confidence”, some nurses described feeling uncomfortable or embarrassed to discuss issues of psychosexual care. They also discussed the influence that a lack of psychosexual care education had on their confidence level and identified this as a barrier to providing care. In the subtheme “Making assumptions”, a variety of patient factors were used by nurses to determine how they thought women would prioritise the discussion of psychosexual issues and they considered how they made care decisions around whether to discuss, or not discuss psychosexual issues based on those assumptions.

During the interviews, almost all of the Western Australian nurses interviewed for this study discussed the importance of developing a trusting relationship with the woman for whom they were providing care. They recognised rapport as a key element to facilitating a conversation around psychosexual issues and this was identified in the sub-theme “Facilitating engagement”. They considered this rapport in relation to how it made them feel, with many describing the need to feel comfortable and confident with the woman before discussing psychosexual issues.

In a UK study investigating the value of therapeutic rapport between doctors and patients, Norfolk, Birdi and Patterson (2009) described therapeutic rapport as a trusting and empathetic relationship between the health professional and their patient, where the goal is to maintain a shared understanding of the patient’s perspective on the issue at hand and to harness this understanding to foster joint decision making. By using verbal and non-verbal communication skills such as smiling, reflecting, allowing silence, asking open questions, checking, acknowledging and mirroring, it is said that doctors are able to

develop an accurate picture of the patient's expectations, thoughts and feelings and these contributed to building strong therapeutic rapport (Norfolk et al., 2009). This quasi-experimental study included 37 General Practitioner trainees who participated in a training programme designed to build rapport with patients. The training group demonstrated significantly greater improvement in all the behavioural outcome measures post-training which included positive engagement, empathic motivation, empathic skills, communication skills and overall rapport. The results of this study are encouraging in support of training programs that aim to improve health professionals' skills in developing rapport with patients.

In 2011, Tay, Hegney and Ang published a systematic review investigating the factors that affect communication between registered nurses and adult cancer patients. From examining three quantitative and five qualitative studies, the authors concluded that communication was influenced by characteristics relating to the nurse, the patient and the environment. These results align with the findings of this Western Australian study where factors were similarly identified. Characteristics relating to the nurse were described in the theme "Nurses are influenced by personal and professional experience and values". Regarding patient characteristics, the theme "Women have unique psychosexual needs" related a variety of traits influencing psychosexual care communication. Environmental characteristics affecting communication were found in the themes "Systems within the health service affect care" and "Society influences attitudes around sexuality". Facilitating factors relating to nurses in the Tay and colleagues (2011) systematic review included genuineness, competency and effective communication skills. Factors that inhibited communication in nurses were demonstrated in those who were task-orientated, who feared death and who had low self-awareness relating to their communication behaviours. The review noted that nurses communicated less effectively when delivering psychosocial care or in emotionally charged situations. In conclusion, the authors recommended that nurses use information-sharing as a strategy to build rapport with patients in a non-threatening manner. They suggested that once rapport was established, patients were more likely to express their

concerns and seek emotional support from the nurse. They also recommended that nurses move away from task-oriented care and that institutions should assist nurses in promoting the use of holistic, psycho-emotional care strategies.

Some nurses in this Western Australian study inferred the concept of rapport, represented under the subtheme 'Facilitating engagement', was equally important to the women as to them. This sentiment was echoed in a Canadian study where health care professionals including physicians, nurses and allied health professionals suggested that having conversations with cancer patients about sexuality is difficult and believed having trust and rapport was important to cancer patients in these discussions (Fitch et al., 2013). More recently, building trust and rapport was also identified by Australian cancer care professionals as an important enabler for positive communication and developing therapeutic relationships, particularly amongst Australian Indigenous patients (Meiklejohn et al., 2016).

In the context of gynaecological cancer, there is limited evidence available around the women's views of the importance of having rapport or a trusting relationship with the health professional when discussing psychosexual issues. The investigation into Western Australian nurses' perspectives examined only one part of the nurse-patient dyad within the context of gynaecological cancer care. Examining the perspective of the women and their views on the importance of rapport may assist nurses in understanding how to foster relationships with women to optimise psychosexual care. One UK study examined the value of the relationship between women with ovarian cancer and nurses whilst providing women with telephone follow-up care (Cox et al., 2008). This relationship was identified as one of the advantages for this nurse-led model of care, by 39% of the 52 women surveyed. It is cited the women felt more comfortable discussing sensitive topics, including sexual issues as a result of this relationship.

Other patient groups with cancer have shared their perspectives on developing a relationship with their care provider. For example, two studies from the UK

investigated men with cancer and supported the positive influence of rapport when discussing intimate issues. One study revealed men with prostate cancer found it difficult to raise psychosexual needs where there was a lack of rapport with the health professional (O'Brien et al., 2011). In a separate study, men with penile cancer identified that the use of appropriate humour during care helped them to foster rapport with health professionals (Branney et al., 2014). Further investigation on the value of rapport is warranted to gain further perspectives of women with gynaecological cancer.

It would be interesting to further explore through research whether nurses underestimate the influence of their professional profile and the value of this status in establishing trust with a patient. Nurses are highly-regarded as trustworthy individuals (Rutherford, 2014) and it is possible that women have a pre-conceived notion of rapport with their nurse even when meeting them for the first time. It is known that face-to-face interaction is not necessarily important to the development of a trusting relationship from the patient's perspective as described in the UK study by Cox et al. (2008) where nurses provided women with ovarian cancer with telephone follow-up care. This idea is also supported by a more recent UK study that investigated 21 colorectal cancer patients participating in nurse-led telephone follow-up. All patients described having developed a trusting relationship with the follow-up nurse despite less than half having actually met or spoken to the nurse in person prior to the intervention (Williamson, Chalmers & Beaver, 2015).

Another area for potential further research is around the nurses' self-awareness of their own sexuality and how this influences their level of comfort and the development of rapport with patients when discussing psychosexual issues. Western Australian nurses in this investigation identified self-awareness of their own sexuality as a topic that influenced their practice, under the subtheme "Values" in Theme 3 "Nurses are influenced by personal and professional experience and values". Exploring their own values and experiences affected whether they felt comfortable discussing psychosexual care with women with some nurses feeling comfortable and others not. Similarly, another Australian

study found health professionals experienced difficulties having conversations around psychosexual care and they suggested these difficulties arise from relating conversations to personal experiences, as such potentially exposing their vulnerability (Hordern & Street, 2007b). Again, in Canada, variability amongst the practice of health professionals discussing issues of sexuality was identified as being influenced by both their personal comfort with the topic and their philosophy of care (Fitch et al., 2013). The critical literature review by Kotronoulas et al. (2009), also discussed evidence that revealed how nurses' level of personal comfort with the conversation was a predictor as to whether sexual health care occurs. The evidence associated with improving health professionals' self-awareness of their own sexuality supports the idea that education and training with content focussing on this concept may help to improve the frequency and quality of psychosexual care provided to cancer patients.

Parallels can be seen between these and other types of so-called 'difficult conversations' where topics are of a personally sensitive or intimate nature, for example end-of-life care and dying (Best, Butow & Olver, 2016; Nguyen, Yates & Osborne, 2014; Schulman-Green, Lin, Smith, Feder Bickell, 2018). Despite acknowledging these conversations are essential to providing quality care, some health professionals continue to struggle with such discussions, or avoid the topic altogether (Kotronoulas et al., 2009). Such was also the case for some of the Western Australian nurses interviewed for this investigation as evidenced in the subtheme "Confidence" under Theme 3 "Nurses are influenced by personal and professional experience and values". Nurses differed in their levels of confidence and comfort in having conversations about psychosexual care which manifested in whether they pursued these discussions with the women.

Similarly, the need for more personal awareness around mortality in order to better discuss these issues with cancer patients was concluded as a potentially helpful strategy in a qualitative grounded theory study conducted in the United States (Rodenbach, Rodenbach, Tejani & Epstein, 2016). Thirty-three physicians, nurse practitioners and physician assistants working in medical or

haematologic oncology identified that their own perspectives on life and death affected their approach to care in the same way that Western Australian nurses identified their “values” and past experiences affected their approach to psychosexual care with women with gynaecological cancer.

Education on using patient-centred communication strategies in difficult conversations with cancer patients about prognosis, end-of-life care and goals of care was evaluated by medical oncology trainees in the United States (Epner & Baile, 2014). They suggested that while some clinicians are innately better at communicating than others, anyone can improve their skills with quality coaching and practice. All 26 participating health professionals positively evaluated the training seminar series which included interactive educational methods to improve the use of strategies such as exploring patients’ perspectives, maintaining mindfulness during intimate conversations and responding to emotion with empathy. In relation to psychosexual care training, similar strategies could be helpful to improve communication methods for what is also identified as a potentially “difficult conversation”.

As identified by Western Australian nurses in this study, the development of rapport and a trusting relationship with women with gynaecological cancer is a facilitating factor in having conversations about psychosexual care. This concept has been identified as helpful when having discussions about sensitive issues with patients of other cancer types however there is limited evidence around the importance of rapport to the patients themselves. Education and training on improving clinicians’ skills may have value and improve the quality and frequency of care provided but more research and evaluation on specific educational models is needed in order to help translate these initiatives globally.

Making assumptions

The nurses from this Western Australian study identified a continual recurrence of assumptions being made around factors influencing the discussion of psychosexual issues. This concept was identified in Theme 3 “Nurses are

influenced by personal and professional experience and values". Nurses described a range of assumptions made by themselves or their colleagues based on a variety of patient factors such as age, sexual history, appearance, health status or 'gut instinct'. Some nurses recognised that they made assumptions and demonstrated insight into this practice. Other participants described the assumptions they made and did not acknowledge that they were making assumptions based on personal and clinical experience or intrinsic values, rather than patient assessment.

Inherent in the core role of nursing is the ability to use skills of assessment to prioritise care and make decisions based on clinical indications and changes in clinical status (NMBA, 2016). In some cases, nurses use evidence-based assessment tools to do this, however at other times they pick up on cues from the patient which often involves making assumptions based on the available information. An Australian grounded theory study investigated how cancer nurses assessed quality of life in oncology wards and palliative care settings (Bahrami & Arbon, 2012). Findings revealed that cues-based Quality of Life assessment was being performed informally by nurses whilst they were communicating with patients and often this was done with uncertainty. It was acknowledged that picking up on cues is not an inappropriate method of assessment to use however where cues-based assessments were performed with uncertainty it was not possible for nurses to know whether their evaluation of the patients' Quality of Life was correct or not.

The assessment of psychosocial issues can be more difficult to achieve than assessing acute clinical needs as there is no set of normal parameters to measure against such is the case with physical signs, i.e. heart rate and blood pressure. The problem with nurses making assessments on the appropriate care to provide for their patients based on cues or assumptions is that issues that may be important to individuals can be missed and therefore contributes to inadequate care. We know from the evidence around providing psychosexual care to patients with cancer (Fitch et al., 2013; Hordern & Street, 2007b; Park et al., 2009; Traa, De Vries, Roukema, Rutten & Den Oudsten, 2014), including

women with gynaecological cancer, that making assumptions is not a concept unique to the cohort of Western Australian nurses interviewed for this study.

Similar to the findings revealed in the subtheme “Making assumptions” (Theme 3), previous research shows that cancer patients and health professionals have mismatched expectations around communication relating to sexuality and that assumptions are made based on stereotypes relating to age, gender, diagnosis, culture and partnership status (Fitch et al., 2013; Hordern & Street, 2007b; Park et al., 2009; Traa et al., 2014). One review reveals a direct link between the sexual attitudes of nurses and the assumptions they make with cancer patients (Kotronoulas et al., 2009). This review suggested attitudes formed around societal myths and assumptions prevent nurses from conceptualising the need to provide sexual health care and inhibits the topic from being raised. It is possible these attitudes may work conversely against the evidence that women prefer health professionals to raise the topic first (Stabile et al., 2017) and contribute to the continuing cycle of silence around the discussion of sexual health.

The findings of this investigation around nurses making assumptions about patients’ needs and thereby influencing their care, are supported by recent studies which demonstrate assumptions being made in other areas of health care. In a qualitative focus group study in the United States it was found that one of the barriers to 48 health care providers during contraceptive counselling was providers making assumptions about pregnancy risk (Akers, Gold, Borrero, Santuci & Schwarz, 2010). Amongst other communication behaviours, timing of the discussion was one example of a mismatch of patient preference in another American qualitative study using Critical Incident Technique comparing perspectives of sexual health communication between 20 breast cancer patients and 20 providers (Canzona et al., 2016). During the interviews, patients expressed disappointment that providers did not initiate discussions about potential negative sexual effects sooner. The authors suggest that providers may find this unrealistic, assuming that an earlier discussion would interfere

with patients processing the wide range of other information they are receiving during the early-stages of diagnosis.

Previous studies using surveys to investigate the attitudes of health care professionals around the provision of psychosexual care have indicated that nurses assumed patients did not expect nurses to address sexual concerns, or that they were a low priority (Julien et al., 2010; Magnan et al., 2005; Magnan & Reynolds, 2006; Zeng et al., 2012). The issue around who initiates a discussion on sexuality is one that again, indicates expectations between patients and health care professionals differ yet investigations suggest that women want to discuss sexual issues with health professionals (Hordern & Street, 2007; Rasmusson & Thome, 2008; Sporn et al., 2015; Stead et al., 2003; Vermeer et al., 2015). Despite this desire, they are often reluctant to raise the topic and prefer it when health care professionals initiate the discussion (Canzona et al., 2016; Stabile et al., 2017; Wilmoth et al., 2011). Kennedy et al. (2015) discuss that while some patients may not prioritise sexual issues, health professionals are not able to predict which patients are in this category without the use of routine assessment.

Nurses in this study acknowledged that assumptions were made either by themselves or others. However, some nurses did not appear to acknowledge they made assumptions, but instead described their assumptions during the interviews. Once again, there was discrepancy around the actual assumptions, suggesting they are based on the nurses' individual attitudes rather than patient assessment.

The international evidence presented (Canzona et al., 2016; Fitch et al., 2013; Hordern & Street, 2007b; Kennedy et al., 2015; Kotronoulas et al., 2009; Park et al., 2009; Traa et al., 2014) suggests that assumptions are being made by nurses and other health care professionals about the need for psychosexual care with their cancer patients, who should receive this care and when they should receive it. This practice may result in insufficient care for women who are wanting to ask questions or receive advice for psychosexual issues but are

waiting for health professionals to initiate the discussion. In order to improve this care and ensure that women are not missing out, solutions need to be implemented to ensure that all women are given the opportunity to discuss psychosexual issues if they have concerns.

Cancer Australia (2016) published a National Framework for Gynaecological Cancer Control and highlighted six priority areas for which to direct their action over the following five years. One of these priority areas is “Promoting a holistic approach to person-centred care” where it is acknowledged that women with gynaecological cancer have specific psychosexual needs which require consideration when providing supportive care. As part of the supportive care approach for women with gynaecological cancer, Cancer Australia (2016) recommend that clinicians provide a systematic approach to supportive care, integrating the provision of a comprehensive needs assessment at key points along the cancer journey. Once patients are assessed, then patients who may benefit from further interventions can be identified and referred appropriately.

The use of formal screening tools may be one way to address the issue of health care professionals making assumptions about the needs of cancer patients, evidenced in the findings of our Western Australian investigation. Screening has previously been used for Western Australian women with gynaecological cancer, using the Distress Thermometer and Problem List Tool (O'Connor et al., 2017). The Distress Thermometer is a single-item tool developed by Roth et al. (1998) and was later combined with a problem checklist by the National Comprehensive Cancer Centre in the United States (Vitek, Rosenweig & Stollings, 2007). The aim of the tool is primarily to detect the presence and level of self-reported psychological distress amongst patients with cancer, identify possible factors that contribute to stress and allow for open communication between cancer patients and health care providers (Vitek et al., 2007). The problem checklist includes 35 items that patients can choose to tick either “yes” or “no” to indicate whether they signify the item is a problem for them. The item “sexual” is included as one of the 35 items, under the heading “physical problems”. A meta-analysis by Ma et al. (2014) reviewed 42 studies that used

the Distress Thermometer conducted between 1997 and 2013 involving 14, 808 patients. They concluded the Distress Thermometer is a valid tool for detecting distress amongst cancer patients but that further research is needed to examine the accuracy and optimal cut-off scores for different global regions and cancer subtypes.

In a mixed methods study, O'Connor et al. (2017) administered the use of the Distress Thermometer and problem list screening tool for 62 Western Australian women with gynaecological cancer over a six-month period. Qualitative data was collected by interviewing six health care professionals working in the oncology setting. At the conclusion of the study, the screening tool was not implemented further into usual clinical practice due to a lack of resources. O'Connor et al. (2017) found that at the time during the tool's use, staff perceived benefits were to validate patients' concerns and issues and use as an icebreaker to aid communication. From the qualitative data, the staff also discussed that using the tool assisted in enhancing their practice, offered a more holistic approach to care and avoided missing important issues. Identified challenges included time to administer the tool and choosing the best time for it to be used.

In Denmark, the use of the Distress Thermometer in 165 survivors of gynaecological cancer was also investigated in a randomised controlled trial aiming to determine the accuracy of the tool in detecting distress in this group of women and thereby guide supportive care (Olesen et al., 2017). Results demonstrated higher anxiety and depression scores in the intervention group where the Distress Thermometer was used and were associated with a greater need for nurse-led, person-centred supportive conversations. The investigators concluded that the Distress Thermometer may perform well as a first stage screening tool for distress but due to a high number of false positives, a second stage of screening is likely needed.

A number of other assessment tools or surveys have been used to detect the need for intervention and support for patients with cancer on issues including

sexuality. Some examples include: The Supportive Care Needs Survey (SCNS) (Boyes, Girgis & Lecathelinais, 2009) the Cancer Survivors Unmet Needs (CaSUN) measure (Hodgkinson et al., 2007), the Psychosocial Needs Questionnaire (PNQ) (Somjai & Chaipoom, 2006), Three Levels of Needs Questionnaire (Seven, Sahin, Yilmaz, & Akyuz, 2016) and the Patient Learning Needs Scale (Akkuzu et al., 2018). The majority of these tools have been used for the identification of supportive care needs during research interventions and there is little available evidence on the use of tools in an ongoing clinical practice model. There is a lack of evidence in the use of any supportive care tool specific to the needs of gynaecological cancer patients either in Australia or internationally.

Use of a tool in clinical practice amongst women with gynaecological cancer would be expected to have similar benefits to those found with the Distress Thermometer and problem checklist in improving the communication between patients and health care professionals on issues including psychosexual care. In addition, integrating the use of such a tool as standard practice could help to overcome the barriers to conversations about sexuality, such as health care professionals waiting for women to raise the topic, by using an evidence-based intervention to identify the need for psychosexual care. It could also assist in reducing the incidence of health professionals making assumptions about who sexuality is an issue for and when is the right time to address these issues.

In summary, it is known that a variety of assumptions are made by nurses and other health care professionals in relation to psychosexual care such as whether it is a priority for certain women with gynaecological cancer, with whom to raise the topic and when is the right time. Health professionals often rely on instinct or cues-based assessment to inform their practice around if and when to discuss psychosexual issues with women. While this is not always an inappropriate strategy, it is risky and may result in women missing out on care that they may have otherwise needed and benefited from. Cancer Australia (2016) advocate for the practice of holistic person-centred care for women with gynaecological cancer and recommend that supportive care is provided using a

systematic approach including the provision of comprehensive supportive care assessment. The combined Distress Thermometer and problem checklist have been used as a needs assessment tool for women with gynaecological cancer however it is suggested that due to a high number of false positives, it may only be appropriate as a first line tool. The development of a supportive care assessment tool specifically for women with gynaecological cancer could be a useful step in helping to achieve the recommendations outlined by Cancer Australia and could incorporate issues specific to the needs of this group of women. The use of such a clinical tool could ensure that women receive comprehensive and appropriate care specific to their unique needs and may help to reduce the effects of health care professional assumptions made about their patients.

Role clarification and expectations on nurses to provide psychosexual care

Amongst the nurses interviewed for this Western Australian study, a lack of clarity was found to exist around expectations on the nurses to provide psychosexual care, whose responsibility it is and what should be discussed. These concepts were captured under theme 4 “Systems within the health service affect care”.

This study confirms findings from previous literature around the existence of barriers to the provision of psychosexual care (Chan et al., 2018; Julien et al., 2010; Magnan et al., 2005; Magnan & Reynolds, 2006; Tsai, 2004; Zeng et al., 2012). While nurses and other health care professionals acknowledge the importance of psychosexual care for women with gynaecological cancer, gaps in practice still exist. Barriers to psychosexual care were identified by Western Australian nurses in this investigation under Theme 2 ‘Women have unique psychosexual needs’, Theme 3 ‘Nurses are influenced by personal and professional experience and values’, Theme 4 ‘Systems within the health service affect care’ and Theme 5 ‘Society influences attitudes around sexuality’.

The difficulty associated with having conversations around topics with which health professionals, including nurses, may feel personally challenged for a variety of reasons is recognised in the cancer care setting (Epner & Baile, 2014; Pavlish, Brown-Saltzman, Fine & Jakel, 2015). In a United States ethnographic study, Pavlish et al. (2015) interviewed 30 oncology nurses and found there is a culture of avoidance in relation to difficult conversations, for example end-of-life care, where they felt ethically challenged. Contributing factors to avoidance included a lack of opportunities to have conversations, insufficient interdisciplinary collaboration and power status differentials (Pavlish et al., 2015). While the discussion of psychosexual care in the Australian environment may not necessarily cause personal ethical conflict for nurses, parallels can be seen around the principle of avoiding conversations that they find challenging in this context.

Barriers associated with having so-called “difficult conversations” in the oncology setting were also acknowledged by Epner and Baile (2014) during the development of their training program to assist medical trainees to improve confidence in communication skills. Again, the focus of the initiative was around discussing end-of-life care, however similar challenges for health professionals discussing psychosexual care exist. In particular, examining how his or her emotions may influence the conversation and that difficult conversations are often avoided due to the possible negative response from the patient (Epner & Baile, 2014). Responses from Western Australian nurses echoed this notion in subthemes ‘Receptiveness’ (Theme 2) and ‘Values’ (Theme 3). These nurses similarly discussed the differences in the patient’s receptiveness to a discussion about psychosexual care as well as how their own personal values and experiences affected the way they delivered care.

A number of nurses interviewed in the Western Australian cohort related that a lack of clarity exists around who holds the responsibility for instigating conversations about psychosexual issues with women. In the subtheme ‘Working as a team’ (Theme 4), some suggested there is an assumption that someone else is doing it or that it is not part of their job. This perception has

been recognised in other studies exploring sexual health care communication. The qualitative UK study by Stead et al. (2003) that investigated the lack of communication regarding sexual issues with women with ovarian cancer, found one of the most frequent reasons cited by the 27 doctors and 16 nurses interviewed for not discussing sexual issues was 'it is not my responsibility'. More recently in Canada, a similar finding was reported from a qualitative descriptive study where interviews were held with 34 multidisciplinary cancer care professionals (Fitch et al., 2013). One of the reasons concluded as to why conversations about sexuality are difficult for professionals was around the perspective on their own role. While some professionals acknowledged discussing sexual issues was part of their responsibility, often this was countered by suggesting it was only their responsibility within certain circumstances. Other professionals considered it was not their role but rather the responsibility of someone else within the multidisciplinary team (Fitch et al., 2013). Some nurses in this investigation similarly related these ideas in subtheme 'Working as a team' (Theme 4) where they described their observation of medical colleagues discussing psychosexual care, or in some cases not discussing it, and also how they themselves referred conversations to specialists when they felt incapable to discuss the issues themselves.

Similarly, also within the Australian cancer care context, the perception of psychosexual care not being their responsibility, or better addressed by other health professionals, was confirmed by 38 health care professionals as a reason for them not discussing sexual issues with patients in a qualitative study by Ussher et al. (2013b). While the health professionals in the Ussher et al. study acknowledged they should raise the issue, a number stated that professionals other than themselves were better positioned to have these conversations. This idea was captured under the theme " 'We are not as equipped as we'd like to be': positioning knowledge, confidence and comfort as barriers to discussion of sexuality after cancer". Participants acknowledged both their own and their colleagues' discomfort with providing psychosexual care as well as relating that others were more equipped to have conversations however, there was no consistency on who the right person would be. One nurse felt it was the doctor's

responsibility, a doctor argued it was the responsibility of the clinical psychologist and another professional countered it was the responsibility of all the team members. This idea that there is lack of role clarity on who should be discussing psychosexual care was also described by our Western Australian nurses.

The avoidance of discussing sexual issues based on the unchecked assumption that somebody else must be doing it was identified by Western Australian nurses in the subtheme 'Being supported by the system' (Theme 4). This idea is also acknowledged in a previous Australian study investigating sexual health communication (Hordern & Street, 2007b). Thirty-two multidisciplinary health professionals including doctors, nurses and social workers were interviewed and using a reflexive inquiry methodology, one of the themes affirmed "Avoidance: I am sure somebody else is addressing the issue" (Hordern & Street, 2007b, p. 54). It was found these assumptions were made both across the multidisciplinary team as well as between physicians.

While all nurses hold a professional responsibility to provide best practice care for their patients (NMBA, 2016), the expectation for what care is provided by nurses cannot rest solely on individual practitioners. If there is an expectation for such care by professional bodies and service providers then it is essential these standards are clearly communicated to practitioners through the establishment and implementation of clear clinical guidelines, documentation prompts and referral pathways. In the absence of such documented minimum standards of care, it may be unrealistic to expect that nurses will provide evidence-based psychosexual care in addition to their other competing duties.

An Irish cross-sectional study of 89 oncology nurses caring for men diagnosed with testicular cancer across five cancer centres were surveyed to identify the barriers and facilitators to discussing sexual issues (Moore, Higgins & Sharek, 2013). Within the findings concerning 'Participants' views on environmental barriers to discussing sexual concerns', a small number of these nurses (n=16, 18%) agreed one of the barriers to discussing sexual concerns was a lack of

support from colleagues or managers and identified the importance of institutional support for psychosexual care (Moore et al., 2013).

In Canada, it has been suggested that a standard of care be established for all patients to be informed about the impact of their cancer treatment on sexuality at the start of their cancer journey (Fitch et al., 2013). This may be one way of similarly addressing the issue of the lack of role clarity and responsibility identified by the Western Australian nurses interviewed. Fitch et al. (2013) suggest the information should be comprehensive, not only including side effects but also how they can potentially impact on self-esteem, personal relationships and physical intercourse. They also discuss that the expectation about having conversations and the roles of health professionals within the team need to be clearly outlined by managers and health leaders in the organisation and that appropriate education needs to be provided to enable clinicians to meet those expectations.

The lack of clarity around who is discussing psychosexual issues and what exactly is being discussed suggests that current documentation systems within organisations are not effective, as discussed in Theme 4 'Systems within the health care system affect care'. This deficit could be improved with the inclusion of a psychosexual assessment and care plan in existing gynaecological cancer documentation. The instigation of such an assessment tool (O'Connor et al., 2017; Olesen et al., 2017) as discussed earlier in this chapter, would assist in standardising this care. However, there must also exist a clarity of expectation from the health service around the provision of psychosexual care.

Clinical practice guidelines are developed by organisations in order to assist clinician and patient decision making by presenting evidence to support best practice (IOM (Institute of Medicine), 2011). They are defined as "statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options" (IOM, 2011, p. 4). Not limited to procedural practices, guidelines must also encompass the process of assessment

and evaluation of care provided to ensure patients' expectations are met (IOM, 2011).

It is recommended that along with the inclusion of an assessment tool and care plan within current gynaecological care documentation, an institution guideline should be established to guide practitioners in the expectation of psychosexual care. This would assist in standardising care, ensuring quality and evidence-based practice, as well as to clarify the responsibility of all members of the multidisciplinary team for psychosexual care provision.

The establishment of guidelines and documentation however, is only one step of the process. Implementation science is a relatively new area of study and is associated with the translation of research into clinical practice (Hoffmann, 2017). It is acknowledged that the uptake of evidence into practice is met with many challenges and the successful adoption of guidelines is associated with a variety of characteristics, with communication at the centre (IOM, 2011). The National Institute for Health and Care Excellence (NICE) (2013) suggest the responsibility for the translation of research into practice and leading a culture of evidence-based practice rests with the executives of health services by ensuring the structural systems are in place to do so.

Education also has a role to play in ensuring practitioners have the skills, knowledge and confidence to effectively deliver quality psychosexual care. In Australia, holistic care practices are required to be addressed during nursing entry-to-practice educational courses due to their existence in the Nursing and Midwifery Board of Australia Registered Nurse Standards for Practice (2016). These practices are required to determine factors affecting the health and well-being of individuals which in the case of gynaecological cancer care would reasonably include issues of sexuality and sexual health. The inclusion of such education in entry-to-practice courses however are only an introduction and it remains the responsibility of nurses to develop their skills from novice to expert throughout their career through ongoing professional development training. Professional bodies and institutions similarly hold a responsibility to ensure

that such educational opportunities are made available to practitioners to assist them in fulfilling these responsibilities. In the case of psychosexual care training for cancer care, it is recommended that this education aim to not only improve knowledge but to specifically address improving nurses' confidence, communication skills and reflection on attitudes relating to sexual issues. The challenge on how this can be achieved remains however with the availability of online education, opportunities exist for interactive and innovative educational initiatives. Whilst examples of these have been developed in the past, i.e the Cancer Australia (2010) "The Psychosexual Care of Women Affected by Gynaecological Cancers" online resource, ongoing funding is required to ensure these resources continue to remain up to date and available to practitioners.

Application of findings

Before providing a summary of recommendations based on the results of this Western Australian investigation, the author would like to acknowledge how the findings have been disseminated and translated to practice to date. In July 2017, a manuscript outlining this study, its results and recommendations was accepted for publication by the European Journal of Oncology Nursing and was subsequently published in October 2017 (Williams, Hauck & Bosco, 2017). Further dissemination of the results was achieved through presentations at national and local events including the Cancer Nurses Society of Australia Annual Congress in Cairns, May 2016, the Women and Infants Research Foundation Rising Stars Event in Perth, September 2016, and the Gynaecological Oncology Strategic Review and Research Meeting held at the study setting in November 2016. In addition to these presentations, the results from this investigation were used to support the educational professional development study day "Psychosexual Care of Women with Gynaecological Cancer" held annually since 2012 at the study setting.

Summary of recommendations

Throughout this discussion, numerous recommendations have been posed with respect to the aim of improving the frequency and quality of psychosexual care

delivery by nurses to women experiencing gynaecological cancer. A summary of these recommendations is provided below:

Clinical Practice Recommendations

- Health services to implement documentation specifically for the assessment of psychosexual issues as standard care for every woman experiencing gynaecological cancer. This strategy would demonstrate that the health institution values psychosexual care as an essential part of gynaecological cancer care and normalises the expectation to assess this patient need.
- Gynaecological cancer health services to implement the use of a clinical supportive care assessment tool to determine the needs of the patients and optimise patient-centred care.
- Health institutions and treating cancer care teams to encourage shared responsibility of psychosexual care amongst the multidisciplinary team, including clarification around the roles and responsibilities of each member of the treating team. One strategy would be through the implementation of clinical guidelines and/or minimum standards of care. This would assist in providing accountability for the delivery of psychosexual care.

Education recommendations

- Health institutions and education providers to implement education programs that not only aim to improve knowledge around the topic of psychosexual care but specifically focus on improving nurses' confidence, communication skills and reflection on attitudes relating to sexual issues, including self-awareness.
- In order to meet the criteria of holistic care practice education stipulated by the Nursing and Midwifery Board of Australia Registered Nurse Standards for Practice (2016), entry to practice nursing programs should ensure the inclusion of education on sexuality and sexual health issues of patients, in particular cancer patients.

Future research recommendations

- Examining women with gynaecological cancer's perspectives of the importance of rapport and a trusting relationship with health care professionals.
- Investigating nurses' perspectives on the influence of their professional profile and the value of this status in establishing trust with a patient.
- Exploring nurses' self-awareness of their own sexuality and how this influences their level of comfort and the development of rapport with patients when discussing psychosexual issues.
- Identifying supportive care needs of Australian women with gynaecological cancer from a qualitative perspective where women are able to share their stories and experiences rather than just respond to pre-determined survey items.
- Investigate the effectiveness of a supportive care clinical assessment tool specific to the needs of gynaecological cancer patients to ensure health care professionals are meeting the needs of the patient.

Study Limitations

A number of limitations were identified throughout the investigation and may influence the capacity for these findings to be translated to other populations or areas of cancer care.

While qualitative data saturation in this instance was achieved with the sample size of 17 nurses, the specific nursing population investigated included nurses working with gynaecological cancer patients attending a specialist tertiary public hospital in Western Australia. The reader will be able to assess the transferability of the findings to other international oncology care contexts based upon the rich description provided around the context of this Western Australian study. For example, other gynaecological cancer care centres within Australia and internationally may be influenced by institutional, epidemiological and political factors not relevant to this population of Western Australian gynaecological cancer nurses. In addition, Australian cultural and

societal views on sexuality could have influenced the findings. Detailed demographic data of the participants was not collected however it is noted that the health institution where the study was based is located in a metropolitan Australian city and the broad socio-economic status of our participants as female middle-income health professionals (i.e. Registered nurses) may have influenced their perspectives on sexuality.

The time period within which the data was collected, namely February to July 2015, could influence the findings as the study context is limited to Western Australia in 2015. Finally, the perspectives of the patients were not investigated and could be pursued with future research as outlined in the recommendations section earlier.

Conclusion

The aim of this study was to investigate the perceptions of Western Australian gynaecological cancer nurses in order to assess factors influencing care in light of the evidence supporting the current state of under provision of psychosexual care for women experiencing gynaecological cancer both in Australia and internationally. By doing so, solutions relevant to this population can then be considered to ensure women are receiving best practice care and optimising their quality of life throughout the period of their cancer treatment as well as into the survivorship phase.

Using qualitative description to analyse the perceptions of 17 Western Australian gynaecological cancer nurses enabled an opportunity to identify the factors affecting care within the context of this cohort of nurses. Five themes emerged from the data collected, namely: (1) Nurses use strategies to aid the conversation (subthemes: Supporting the woman, Facilitating engagement); (2) Women have unique psychosexual needs (subthemes: Diversity, Receptiveness); (3) Nurses are influenced by personal and professional experience and values (subthemes: Confidence, Values, Making assumptions); (4) Systems within the health service affect care (subthemes: Being supported

by the system, Working as a team); and (5) Society influences attitudes around sexuality.

The findings revealed a number of key concepts that are important to consider in order to devise strategies to improve the amount and quality of psychosexual care provided to women experiencing gynaecological cancer. The influence of rapport between the woman and the nurse, the significance of health care professionals making assumptions about women and their care, and role clarification and expectations on nurses to discuss psychosexual issues were discussed to provide insight into how these concepts are influenced and provide examples of where parallels can be drawn in other areas of health care.

The findings of this study are significant as they provide insight into the perceptions of how Western Australian nurses conceptualise psychosexual care provision for women experiencing gynaecological cancer, a population which had not previously been investigated. As a result of these findings, recommended strategies to improve service provision include adapting guidelines and documentation to include assessment of psychosexual issues as standard care, encouraging shared responsibility of psychosexual care amongst the multidisciplinary team and implementing education programs focussed on improving nurses' confidence and communication skills. Gynaecological cancer care services could consider implementing these strategies in order to improve care provision and ultimately improve the quality of life for these vulnerable women.

References

- Abbott-Anderson, K., & Kwekkeboom, K. L. (2012). A systematic review of sexual concerns reported by gynecological cancer survivors. *Gynecologic Oncology*, 124(3), 477-489. doi: 10.1016/j.ygyno.2011.11.030
- Akers, A. Y., Gold, M.A., S., Borrero, S., Santucci A., & Schwarz, E. B. (2010). Providers' perspectives on challenges to contraceptive counseling in primary care settings. *Journal of Women's Health*, 19(6), 1163-1170.
- Akkuzu G., Kurt G., Guvenc G., Kok G., Simsek S., Dogrusoy S., & Ayhan A. (2018). Learning needs of gynecologic cancer survivors. *Journal of Cancer Education*, 33(3), 544-550.
- Ali, A. (2014). Reproductive factors and the risk of endometrial cancer. *International Journal of Gynecological Cancer*, 24(3), 384-393.
- Andersen, B. L. (1990). How cancer affects sexual functioning. *Oncology*, 4(6), 81-88; discussion 92.
- Anderson, J. L. (2013). Acknowledging female sexual dysfunction in women with cancer. *Clinical Journal of Oncology Nursing*, 17(3), 233-235.
- Andrews, M., Goldberg, K., & Kaplan, H. (1996). *Nurse's legal handbook* (3rd ed.). Springhouse, PA: Springhouse Corporation.
- Annon, J. S. (1976). The PLISSIT Model: A proposed conceptual scheme for the behavioral treatment of sexual problems. *Journal of Sex Education and Therapy*, 2(1), 1-15. doi:10.1080/01614576.1976.11074483
- Audette, C., & Waterman, J. (2010). The sexual health of women after gynecologic malignancy. *Journal of Midwifery and Womens Health*, 55(4), 357-362. doi: 10.1016/j.jmwh.2009.10.016
- Australian Bureau of Statistics. (2018). 2016 Census Data. Retrieved 5 September 2018, from <http://www.abs.gov.au>

- Australian Government Department of Health. (2018). HPV (Human papillomavirus). Retrieved from <https://beta.health.gov.au/health-topics/hpv-human-papillomavirus>
- Australian Government National Cervical Screening Program. (n.d.). Understanding the national cervical screening program management pathway: A guide for healthcare providers. Retrieved from [http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/C2058A7D155867ACCA2581C400082790/\\$File/CAN174-Understanding-the-National-Cervical-Screening-Program-Management-Pathway.pdf](http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/C2058A7D155867ACCA2581C400082790/$File/CAN174-Understanding-the-National-Cervical-Screening-Program-Management-Pathway.pdf)
- Australian Institute of Health and Welfare. (2017). Australian cancer incidence and mortality (ACIM) books. Cervical Cancer. Canberra: Australian Institute of Health and Welfare. Retrieved from <https://www.aihw.gov.au/reports/cancer/acim-books/contents/acim-books>
- Australian Institute of Health and Welfare & Cancer Australia. (2012). Gynaecological cancers in Australia: An overview. Cancer Series no. 70. Cat. no. CAN 66). Canberra: Australian Institute of Health and Welfare.
- Ayaz, S. (2013). Sexuality and nursing process: a literature review. *Sexuality & Disability*, 31(1), 3-12. doi: 10.1007/s11195-012-9280-6
- Bahrami, M., & Arbon, P. (2012). How do nurses assess quality of life of cancer patients in oncology wards and palliative settings? *European Journal of Oncology Nursing*, 16(3), 212-219. doi: <http://dx.doi.org/10.1016/j.ejon.2011.05.003>
- Bal, M., Yilmaz, S., & Beji, N. (2013). Sexual health in patients with gynecological cancer: A qualitative study. *Sexuality & Disability*, 31(1), 83-92. doi: 10.1007/s11195-012-9263-7

- Barlow, E., Hacker, N., Hussain, R., & Parmenter, G. (2014). Sexuality and body image following treatment for early-stage vulvar cancer: A qualitative study. *Journal of Advanced Nursing*, 70(8), 1856-1866.
- Best, M., Butow, P., & Olver, I. (2016). Why do we find it so hard to discuss spirituality? A qualitative exploration of attitudinal barriers. *Journal of Clinical Medicine*, 5(9), 77. doi: 10.3390/jcm5090077
- Booth, K., Beaver, K., Kitchener, H., O'Neill, J., & Farrell, C. (2005). Women's experiences of information, psychological distress and worry after treatment for gynaecological cancer. *Patient Education and Counseling*, 56(2), 225-232. doi: <http://dx.doi.org/10.1016/j.pec.2004.02.016>
- Boyes, A., Girgis, A., & Lecathelinais, C. (2009). Brief assessment of adult cancer patients' perceived needs: Development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34). *Journal of Evaluation in Clinical Practice*, 15(4), 602-6.
- Brandenburg, U., & Bitzer, J. (2009). The challenge of talking about sex: The importance of patient-physician interaction. *Maturitas*, 63(2), 124-127. doi: <http://dx.doi.org/10.1016/j.maturitas.2009.03.019>
- Branney, P., Witty, K., Braybrook, D., Bullen, K., White, A., & Eardley, I. (2014). Masculinities, humour and care for penile cancer: A qualitative study. *Journal of Advanced Nursing*, 70(9), 2051-2060. doi: 10.1111/jan.12363
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi: 10.1191/1478088706qp063oa
- Brotto, L., Heiman, J., Goff, B., Greer, B., Lentz, G., Swisher, E., . . . Van Blaricom, A. (2008). A psychoeducational intervention for sexual dysfunction in women with gynecologic cancer. *Archives of Sexual Behavior*, 37(2), 317-329.

- Cancer Australia. (2010). The psychosexual care of women affected by gynaecological cancers: A training module for health professionals (PSGC). From <http://modules.cancerlearning.gov.au/psgc/>
- Cancer Australia. (2012). Intimacy and sexuality for women with gynaecological cancer - starting a conversation. From <https://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/intimacy-and-sexuality-women-gynaecological-cancer-starting-conversation>
- Cancer Australia. (2016). *National framework for gynaecological cancer control*. Surry Hills, NSW: Cancer Australia.
- Cancer Australia. (2017). Gynaecological cancer statistics. Retrieved 29 June 2017, from <https://gynaecological-cancer.canceraustralia.gov.au/statistics>
- Cancer Council Australia Cervical Cancer Screening Guidelines Working Party. (2016). National cervical screening program: Guidelines for the management of screen-detected abnormalities, screening in specific populations and investigation of abnormal vaginal bleeding. Cancer Council Australia, Sydney. Retrieved from https://wiki.cancer.org.au/australiawiki/images/a/ad/National_Cervical_Screening_Program_guidelines_long-form_PDF.pdf.
- Canzona, M. R., Garcia, D., Fisher, C. L., Raleigh, M., Kalish, V., & Ledford, C. J. (2016). Communication about sexual health with breast cancer survivors: Variation among patient and provider perspectives. *Patient Education and Counseling*, 99, 1814-1820.
- Chan, R.J., Button, E., Thomas, A., Gates., & Yates, P. (2018). Nurses attitudes and practices towards provision of survivorship care for people with a haematological cancer on completion of treatment. *Supportive Care in Cancer*, 26(5), 1401-1409.

- Cleary, V., & Hegarty, J. (2011). Understanding sexuality in women with gynaecological cancer. *European Journal of Oncology Nursing*, 15(1), 38-45.
- Cleary, V., Hegarty, J., & McCarthy, G. (2011). Sexuality in Irish women with gynecologic cancer. *Oncology Nursing Forum*, 38(2), E87-96. doi: 10.1188/11.onf.e87-e96
- Cleary, V., McCarthy, G., & Hegarty, J. (2012). Development of an educational intervention focused on sexuality for women with gynecological cancer. *Journal of Psychosocial Oncology*, 30(5), 535-555. doi: 10.1080/07347332.2012.703767
- Colorafi, K., & Evans, B. (2016). Qualitative descriptive methods in health science research. *HERD : Health Environments Research & Design Journal*, 9(4), 16-25.
- Cook, O., McIntyre, M., Recoche, K., & Lee, S. (2017). Experiences of gynaecological cancer patients receiving care from specialist nurses: A qualitative systematic review. *JBI Database of Systematic Reviews and Implementation Reports*, 15(8), 2087-2112. doi: 10.11124/JBISRIR-2016-003126
- Cox, A., Bull, E., Cockle Hearne, J., Knibb, W., Potter, C., & Faithfull, S. (2008). Nurse led telephone follow up in ovarian cancer: A psychosocial perspective. *European Journal of Oncology Nursing*, 12(5), 412-417.
- Creswell, J. (2013). *Research design: Qualitative, quantitative and mixed methods approaches* (4th ed.). Thousand Oaks: Sage Publications.
- DeSimone, C. P., Van Ness J.S., Cooper, A. L., Modesitt, S. C., DePriest, P. D., Ueland, F. R,... van Nagell Jr, J. R. (2007). The treatment of lateral T1 and T2 squamous cell carcinomas of the vulva confined to the labium majus or minus. *Gynecologic Oncology*, 104, 390-395.

- Ekwall, E., Ternestedt, B., & Sorbe, B. (2003). Important aspects of health care for women with gynecologic cancer. *Oncology Nursing Forum*, 30(2 part 1), 313-319. doi: 10.1188/03.ONF.313-319
- Epner, D. E., & Baile, W. F. (2014). Difficult conversations: Teaching medical oncology trainees communication skills one hour at a time. *Academic Medicine*, 89(4), 578-584. doi: 10.1097/acm.0000000000000177
- Etchegary, H., Dicks, E., Watkins, K., Alani, S., & Dawson, L. (2015). Decisions about prophylactic gynecologic surgery: A qualitative study of the experience of female Lynch syndrome mutation carriers. *Hereditary Cancer in Clinical Practice*, 13(1), 10.
- Faghani, S., & Ghaffari, F. (2016). Effects of sexual rehabilitation using the PLISSIT model on quality of sexual life and sexual functioning in post-mastectomy breast cancer survivors. *Asian Pacific Journal of Cancer Prevention*, 17(11), 4845-4851.
- Falk, S., & Dizon, D. (2013). Sexual dysfunction in women with cancer. *Fertility and Sterility*, 100(4), 916-921.
- Ferreira, S. M. d. A., Gozzo, T. d. O., Panobianco, M. S., dos Santos, M. A., & de Almeida, A. M. (2015). Barriers for the inclusion of sexuality in nursing care for women with gynecological and breast cancer: Perspective of professionals. *Revista Latino-Americana de Enfermagem*, 23, 82-89.
- Fitch, M. I., Beaudoin, G., & Johnson, B. (2013). Challenges having conversations about sexuality in ambulatory settings: Part II--health care provider perspectives. *Canadian Oncology Nursing Journal*, 23(3), 182-196.
- Flynn, P., Kew, F., & Kisely, S. R. (2009). Interventions for psychosexual dysfunction in women treated for gynaecological malignancy. *Cochrane Database Systematic Review* (2), Cd004708. doi: 10.1002/14651858.CD004708.pub2
- Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20(9), 1408-1416.

- Gamel, C., Hengeveld, M., & Davis, B. (2000). Informational needs about the effects of gynaecological cancer on sexuality: A review of the literature. *Journal of Clinical Nursing*, 9(5), 678-688 611p. doi: 10.1046/j.1365-2702.2000.00416.x
- Gilbert, E., Perz, J., & Ussher, J. M. (2016). Talking about sex with health professionals: The experience of people with cancer and their partners. *European Journal of Cancer Care (English Edition Print)*, 25(2), 280-293.
- Gilbert, E., Ussher, J., & Perz, J. (2011). Sexuality after gynaecological cancer: A review of the material, intrapsychic, and discursive aspects of treatment on women's sexual-wellbeing. *Maturitas*, 70(1), 42-57.
- Government of Western Australia, Department of Health. (2009). *Gynaecologic Cancer Model of Care: 6 November 2008*. Perth: Cancer and Palliative Care Network, Western Australia. Retrieved from <http://www.healthnetworks.health.wa.gov.au/modelsofcare/docs/Gynaec-Oncology%20Model%20of%20Care.pdf>.
- Government of Western Australia, Department of Health. (n.d.). Western Australian Cancer Registry: Cancer incidence and mortality in Western Australia: ISSN 0816-2999. Retrieved from http://www.health.wa.gov.au/wacr/statistics/stats_full.cfm
- Government of Western Australia, North Metropolitan Health Service, King Edward Memorial Hospital. (n.d.). Our Services: Service Directory: Gynaecology Services. Retrieved from <https://www.kemh.health.wa.gov.au/Our-services/Service-directory/Gynaecology-Services-including-cancer-care>
- Grimm, D., Hasenburg, A., Eulenburg, C., Steinsiek, L., Mayer, S., Eltrop, S., . . . Woelber, L. (2015). Sexual activity and function in patients with gynecological malignancies after completed treatment. *International Journal of Gynecological Cancer*, 25(6), 1134-1141. doi: 10.1097/igc.0000000000000468

- Guba, E. G. (1981). ERIC/ECTJ Annual review paper: Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology*, 29(2), 75-91.
- Hodgkinson, K., Butow, P., Hunt, G.E., Pendlebury, S., Hobbs, K.M., Lo, S.K., & Wain, G. (2007). The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: The CaSUN (Cancer Survivors' Unmet Needs measure). *Psychooncology*, 16(9), 796-804.
- Hoffmann, T. (2017). *Evidence-based practice across the health professions / Tammy Hoffmann, Sally Bennett, Chris Del Mar* (3rd ed.): Chatswood, N.S.W. : Elsevier Australia (a division of Reed International Books Australia Pty Ltd.).
- Holosko, M.J. & Thyer, B.A. (2011). *Pocket glossary for commonly used research terms*. Thousand Oaks: Sage Publications.
- Holt, K. A., Hansen, H. P., & Mogensen, O. (2014). Supportive care needs for women with gynecological cancer and their relatives during the prediagnostic period. *Cancer Nursing*, 37(6), 457-467.
- Hopkins, T. G., Stavrakas, C., Gabra, H., Fallowfield, L., Hood, C., & Blagden, S. (2015). Sexual activity and functioning in ovarian cancer survivors: An internet-based evaluation. *Climacteric*, 18(1), 94-98.
- Hordern, A. (2008). Intimacy and sexuality after cancer: A critical review of the literature. *Cancer Nursing*, 31(2), E9-17. doi: 10.1097/01.NCC.0000305695.12873.d5
- Hordern, A. J., & Street, A. F. (2007a). Communicating about patient sexuality and intimacy after cancer: Mismatched expectations and unmet needs. *The Medical Journal of Australia*, 186(5), 224-227.
- Hordern, A. J., & Street, A. F. (2007b). Let's talk about sex: Risky business for cancer and palliative care clinicians. *Contemporary Nurse*, 27(1), 49-60. doi: 10.5555/conu.2007.27.1.49

- Iavazzo, C., Johnson, K., Savage, H., Gallagher, S., Datta, M., & Winter Roach, B. A. (2015). Sexuality issues in gynaecological oncology patients: Post treatment symptoms and therapeutic options. *Archives of Gynecology and Obstetrics*, 291(3), 653-656.
- Institute of Medicine (IOM). (2011). *Clinical practice guidelines we can trust*. Washington: The National Academies Press.
- Jefferies, H., & Clifford, C. (2011). A literature review of the impact of a diagnosis of cancer of the vulva and surgical treatment. *Journal of Clinical Nursing*, 20(21-22), 3128-3142.
- Jeppesen, M. M., Mogensen, O., Dehn, P., & Jensen, P. T. (2015). Needs and priorities of women with endometrial and cervical cancer. *Journal of Psychosomatic Obstetrics & Gynaecology*, 36(3), 122-132. doi:10.3109/0167482x.2015.1059417
- Julien, J., Thom, B., & Kline, N. (2010). Identification of barriers to sexual health assessment in oncology nursing practice. *Oncology Nursing Forum*, 37(3), E186-190.
- Juraskova, I., Butow, P., Bonner, C., Robertson, R., & Sharpe, L. (2013). Sexual adjustment following early stage cervical and endometrial cancer: Prospective controlled multi-centre study. *Psychooncology*, 22(1), 153-159. doi:10.1002/pon.2066
- Kennedy, V., Abramsohn, E., Makelarski, J., Barber, R., Wroblewski, K., Tenney, M., . . . Lindau, S. T. (2015). Can you ask? We just did! Assessing sexual function and concerns in patients presenting for initial gynecologic oncology consultation. *Gynecologic Oncology*, 137(1), 119-124. doi: <http://dx.doi.org/10.1016/j.ygyno.2015.01.451>
- Kim, S. I., Lee, Y., Lim, M. C., Joo, J., Park, K., Lee, D. O., & Park, S. Y. (2015). Quality of life and sexuality comparison between sexually active ovarian cancer survivors and healthy women. *Journal of Gynecological Oncology*, 26(2), 148-154. doi: 10.3802/jgo.2015.26.2.148

- Kotronoulas, G., Papadopoulou, C., & Patiraki, E. (2009). Nurses' knowledge, attitudes, and practices regarding provision of sexual health care in patients with cancer: Critical review of the evidence. *Supportive Care in Cancer*, 17(5), 479-501.
- Krauss, S. E. (2005). Research paradigms and meaning making: A primer. *The Qualitative Report*, 10(4), 758-770.
- Lara, L. A., de Andrade, J. M., Consolo, F. D., & Romao, A. P. (2012). Women's poorer satisfaction with their sex lives following gynecologic cancer treatment. *Clinical Journal of Oncology Nursing*, 16(3), 273-277. doi: 10.1188/12.cjon.273-277
- Lee, J. T., Lin, H. H., Tsai, J. L., Chen, C. P., Huang, K. G., & Lien, A. S. (2015). Transformation of sexual expression in Taiwanese women after treatment for gynecological cancer. *Cancer Nursing*, 38(6), 475-483. doi: 10.1097/ncc.0000000000000224
- Leedy, P.D., & Ormrod, J.E. (2015). *Practical research: Planning and design* (11th ed.). Harlow: Pearson Education.
- Lindau, S. T., Gavrilova, N., & Anderson, D. (2007). Sexual morbidity in very long term survivors of vaginal and cervical cancer: A comparison to national norms. *Gynecologic Oncology*, 106(2), 413-418. doi: 10.1016/j.ygyno.2007.05.017
- Ma, X., Zhang, J., Zhong, W., Shu, C., Wang, F., Wen J., . . . Liu, L. (2014). The diagnostic role of a short screening tool--the distress thermometer: A meta-analysis. *Support Care Cancer*, 22(7), 1741-55.
- Macdowall, W., Parker, R., Nanchahal, K., Ford, C., Lowbury, R., Robinson, A., . . . Wellings, K. (2010). 'Talking of Sex': Developing and piloting a sexual health communication tool for use in primary care. *Patient Education and Counseling*, 81(3), 332-337. doi: <http://dx.doi.org/10.1016/j.pec.2010.10.027>

- Magnan, M., & Norris, D. (2008). Nursing students' perceptions of barriers to addressing patient sexuality concerns. *The Journal of Nursing Education, 47*(6), 260-268.
- Magnan, M., & Reynolds, K. (2006). Barriers to addressing patient sexuality concerns across five areas of specialization. *Clinical Nurse Specialist, 20*(6), 285-292.
- Magnan, M., Reynolds, K., & Galvin, E. (2005). Barriers to addressing patient sexuality in nursing practice. *Medsurg Nursing, 14*(5), 282-289; quiz 290.
- McCallum, M., Jolicoeur, L., Lefebvre, M., Babchishin, L. K., Robert-Chauret, S., Le, T., & Lebel, S. (2014). Supportive care needs after gynecologic cancer: Where does sexual health fit in? *Oncology Nursing Forum, 41*(3), 297-306. doi: 10.1188/14.ONF.297-306
- Meiklejohn, J. A., Adams, J., Valery, P. C., Walpole, E. T., Martin, J. H., Williams, H. M., & Garvey, G. (2016). Health professional's perspectives of the barriers and enablers to cancer care for Indigenous Australians. *European Journal of Cancer Care, 25*(2), 254-261.
- Mick, J. (2007). Sexuality assessment: 10 strategies for improvement. *Clinical Journal of Oncology Nursing, 11*(5), 671-675.
- Mick, J., Hughes, M., & Cohen, M.Z. (2004). Using the BETTER model to assess sexuality. *Clinical Journal of Oncology Nursing, 8*(1), 84-86.
- Miles, B.M., Huberman, A.M., & Saldaña, J. (2014). *Qualitative data analysis: A methods sourcebook*. Thousand Oaks: Sage Publications.
- Moore, A., Higgins, A., & Sharek, D. (2013). Barriers and facilitators for oncology nurses discussing sexual issues with men diagnosed with testicular cancer. *European Journal of Oncology Nursing, 17*(4), 416-422. doi: <http://dx.doi.org/10.1016/j.ejon.2012.11.008>
- National Health and Medical Research Council. (2007 (Updated May 2015)). *National Statement on Ethical Conduct in Human Research*. Canberra:

- National Health and Medical Research Council, the Australian Research Council and the Australian Vice-Chancellors' Committee.
- National Institute for Health and Care Excellence (NICE). (2013). Into practice guide: Process and methods. Retrieved from nice.org.uk/process/pmg30
- Nguyen, L.T., Yates, P., & Osborne, Y. (2014). Palliative care knowledge, attitudes and perceived self-competence of nurses working in Vietnam. *International Journal of Palliative Nursing*, 20(9), 448-456. doi: 10.12968/ijpn.2014.20.9.448
- Nursing and Midwifery Board of Australia (NMBA). (2016). Registered nurse standards for practice. Retrieved from <http://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements/Professional-standards/registered-nurse-standards-for-practice.aspx>
- Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description - the poor cousin of health research? *BMC Medical Research Methodology*, 9, 52. doi: 10.1186/1471-2288-9-52
- Norfolk, T., Birdi K., & Patterson, F. (2009). Developing therapeutic rapport: A training validation study. *Quality in Primary Care*, 17(2), 99-106.
- O'Brien, R., Rose, P., Campbell, C., Weller, D., Neal, R. D., Wilkinson, C., . . . Watson, E. (2011). "I wish I'd told them": A qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment. *Patient Education and Counseling*, 84(2), 200-207. doi: 10.1016/j.pec.2010.07.006
- O'Connor, M., Tanner, P. B., Miller, L., Watts K.J., & Musiello, T. (2017). Detecting distress: Introducing routine screening in a gynecologic cancer setting. *Clinical Journal of Oncology Nursing*, 21(1), 79-85.
- Olesen, M. L., Hansen, M. K., Hansson, H., Ottesen, B., Andersen, K. K., & Zoffmann, V. (2017). The distress thermometer in survivors of

- gynaecological cancer: Accuracy in screening and association with the need for person-centred support. *Supportive Cancer Care*. LID - 10.1007/s00520-017-3935-x [doi]. (1433-7339 (Electronic)).
- Olsson, C., Berglund, A.-L., Larsson, M., & Athlin, E. (2012). Patient's sexuality - A neglected area of cancer nursing? *European Journal of Oncology Nursing*, 16(4), 426-431.
- Park, E., Norris, R., & Bober, S. (2009). Sexual health communication during cancer care: Barriers and recommendations. *The Cancer Journal*, 15(1), 74-77.
- Pavlish, C., Brown-Saltzman, K., Fine, A., & Jakel, P. (2015). A culture of avoidance: Voices from inside ethically difficult clinical situations. *Clinical Journal of Oncology Nursing*, 19(2), 159-165. doi: 10.1188/15.cjon.19-02ap
- Philp, S., Barnett, C., D'Abrew, N., & White, K. (2017). Nurse confidence in gynaecological oncology practice and the evaluation of a professional development module. *Contemporary Nurse*, 53(2), 203-216.
- Polit, D. F., & Beck, C. T. (2014). *Essentials of nursing research: Appraising evidence for nursing practice* (8th ed.). Philadelphia: Wolters Kluwer Health Lippincott Williams & Wilkins.
- Rasmusson, E.-m., & Thomé, B. (2008). Women's wishes and need for knowledge concerning sexuality and relationships in connection with gynecological cancer disease. *Sexuality and Disability*, 26(4), 207-218. doi: <http://dx.doi.org/10.1007/s11195-008-9097-5>
- Reis, N., Beji, N., & Coskun, A. (2010). Quality of life and sexual functioning in gynecological cancer patients: Results from quantitative and qualitative data. *European Journal of Oncology Nursing*, 14(2), 137-146.
- Robertson, R. (2005). Sexuality and body image. In *Gynaecological Cancer Care: A Guide to Practice* (Lancaster, L., & Nattress, K., eds). Ausmed Publications, Melbourne.

- Rodenbach, R.A., Rodenbach, K.E., Tejani, M.A., & Epstein, R.M. (2016). Relationships between personal attitudes about death and communication with terminally ill patients: How oncology clinicians grapple with mortality. *Patient Education and Counseling*, 99(3), 356-363.
- Roth, A. J., Kornblith, A.B., Batel-Copel L., Peabody E., Scher H.I., & Holland, J. C. (1998). Rapid screening for psychologic distress in men with prostate carcinoma: A pilot study. *Cancer*, 82(10), 1904-1908.
- Rutherford, M. M. (2014). The value of trust to nursing. *Nursing Economic\$*, 32(6), 283-288; 327; quiz 289.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334-340.
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health*, 33(1), 77-84. doi: 10.1002/nur.20362
- Saunamäki, N., Andersson, M., & Engström, M. (2010). Discussing sexuality with patients: Nurses' attitudes and beliefs. *Journal of Advanced Nursing*, 66(6), 1308-1316.
- Schneider, Z., Whitehead, D., LoBiondo-Wood, G., & Haber, J. (2016). *Nursing and midwifery research: Methods and appraisal for evidence-based practice* (5th ed.). Chatswood, NSW: Elsevier Australia.
- Schulman-Green, D., Lin, J.J., Smith, C.B., Feder, S., & Bickell, N.A. (2018). Facilitators and barriers to oncologists' conduct of goals of care conversations. *Journal of Palliative Care*, 33(3), 143-148. doi: 10.1177/0825859718777361
- Sekse, R. J., Hufthammer, K. O., & Vika, M. E. (2016). Sexual activity and functioning in women treated for gynaecological cancers. *Journal of Clinical Nursing*. doi: 10.1111/jocn.13407

- Seven, M., Sahin, E., Yilmaz, S., & Akyuz, A. (2016). Palliative care needs of patients with gynaecologic cancer. *Journal of Clinical Nursing*, 25(21-22), 3152-3159. doi: 10.1111/jocn.13280
- Shell, J. A. (2002). Evidence-based practice for symptom management in adults with cancer: Sexual dysfunction. *Oncology Nursing Forum*, 29(1), 53-66.
- Somjai A., & Chaipoom A. (2006). Psychosocial needs of women with cancer of the reproductive system: A comparison between Buddhist and Muslim patients in Thailand. *Mental Health, Religion & Culture*, 9, 379-388.
- Southard, N. Z., & Keller, J. (2009). The importance of assessing sexuality: A patient perspective. *Clinical Journal of Oncology Nursing*, 13(2), 213-217. doi: 10.1188/09.cjon.213-217
- Sporn, N. J., Smith, K. B., Pirl, W. F., Lennes, I. T., Hyland, K. A., & Park, E. R. (2015). Sexual health communication between cancer survivors and providers: How frequently does it occur and which providers are preferred? *Psychooncology*, 24(9), 1167-1173. doi: 10.1002/pon.3736
- Stabile, C., Goldfarb, S., Baser, R. E., Goldfrank, D. J., Abu-Rustum, N. R., Barakat, R. R., . . . Carter, J. (2017). Sexual health needs and educational intervention preferences for women with cancer. *Breast Cancer Research and Treatment*, 165(1), 77-84. doi: 10.1007/s10549-017-4305-6
- Stabile, C., Gunn, A., Sonoda, Y., & Carter, J. (2015). Emotional and sexual concerns in women undergoing pelvic surgery and associated treatment for gynecologic cancer. *Translational Andrology and Urology*, 4(2), 169-185. doi: 10.3978/j.issn.2223-4683.2015.04.03
- Stead, M. L., Brown, J. M., Fallowfield, L., & Selby, P. (2003). Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *British Journal of Cancer*, 88(5), 666-671.

- Streubert, H. J., & Carpenter, D. R. (2011). *Qualitative research in nursing: Advancing the humanistic imperative* (5th ed.). Philadelphia: Wolters Kluwer Health Lippincott Williams & Wilkins.
- Sung, S. C., Jiang, H. H., Chen, R. R., & Chao, J. K. (2016). Bridging the gap in sexual healthcare in nursing practice: Implementing a sexual healthcare training programme to improve outcomes. *Journal of Clinical Nursing*, 25(19-20).
- Tay, L. H., Hegney, D., & Ang, E. (2011). Factors affecting effective communication between registered nurses and adult cancer patients in an inpatient setting: A systematic review. *International Journal of Evidence-Based Healthcare*, 9(2), 151-164. doi: 10.1111/j.1744-1609.2011.00212.x
- Traa, M. J., De Vries, J., Roukema, J. A., Rutten, H. J., & Den Ouden, B. L. (2014). The sexual health care needs after colorectal cancer: The view of patients, partners, and health care professionals. *Supportive Care in Cancer*, 22(3), 763-772. doi: 10.1007/s00520-013-2032-z
- Tsai, Y.-F. (2004). Nurses' facilitators and barriers for taking a sexual history in Taiwan. *Applied Nursing Research*, 17(4), 257-264.
- Ussher, J., Perz, J., Gilbert, E., Wong, W. K. T., & Hobbs, K. (2013a). Renegotiating sex and intimacy after cancer: Resisting the coital imperative. *Cancer Nursing*, 36(6), 454-462.
- Ussher, J., Perz, J., Gilbert, E., Wong, W. K. T., Mason, C., Hobbs, K., & Kirsten, L. (2013b). Talking about sex after cancer: A discourse analytic study of health care professional accounts of sexual communication with patients. *Psychology & Health*, 28(12), 1370-1390.
- Vermeer, W. M., Bakker, R. M., Kenter, G. G., Stiggelbout, A. M., & Ter Kuile, M. M. (2016). Cervical cancer survivors' and partners' experiences with sexual dysfunction and psychosexual support. *Supportive Care in Cancer*, 24(4), 1679-1687. doi: 10.1007/s00520-015-2925-0

- Vermeer, W. M., Bakker, R. M., Stiggelbout, A. M., Creutzberg, C. L., Kenter, G. G., & ter Kuile, M. M. (2015). Psychosexual support for gynecological cancer survivors: Professionals' current practices and need for assistance. *Supportive Care in Cancer*, 23(3), 831-839. doi: 10.1007/s00520-014-2433-7
- Vitek, L., Rosenzweig M.Q., & Stollings, S. (2007). Distress in patients with cancer: Definition, assessment, and suggested interventions. *Clinical Journal of Oncology Nursing*, 11(3), 413-418.
- Vogt, W. P., & Johnson, R. B. (2011). *Dictionary of statistics and methodology: A nontechnical guide for the social sciences* (4th ed.). Thousand Oaks: Sage Publications Inc.
- Wang, L., Pierdomenico, A., Lefkowitz, A., & Brandt, R. (2015). Female sexual health training for oncology providers: New applications. *Sexual Medicine*, 3(3), 189-197.
- Weijmar Schultz, W. C., van de Wiel, H. B., Bouma, J., Janssens, J., & Littlewood, J. (1990). Psychosexual functioning after the treatment of cancer of the vulva. A longitudinal study. *Cancer*, 66(2), 402-407.
- Williams, N.F., Hauck, Y.L., & Bosco, A.M. (2017). Nurses' perceptions of providing psychosexual care for women experiencing gynaecological cancer. *European Journal of Oncology Nursing*, 30, 35-42.
- Williamson, S., Chalmers, K., & Beaver, K. (2015). Patient experiences of nurse-led telephone follow-up following treatment for colorectal cancer. *European Journal of Oncology Nursing*, 19(3), 237-243. doi: <http://dx.doi.org/10.1016/j.ejon.2014.11.006>
- Willis, E., Reynolds, L.E., & Keleher, H. (2012). *Understanding the Australian health care system* (2nd ed.). Chatswood, Australia: Churchill Livingstone.
- Wilmoth, M., Hatmaker Flanigan, E., LaLoggia, V., & Nixon, T. (2011). Ovarian cancer survivors: Qualitative analysis of the symptom of sexuality. *Oncology Nursing Forum*, 38(6), 699-708.

- Wilmoth, M. C., & Spinelli, A. (2000). Sexual implications of gynecologic cancer treatments. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 29(4), 413-421.
- Woods, N. F. (1987). Toward a holistic perspective of human sexuality: Alterations in sexual health and nursing diagnoses. *Holistic Nursing Practice*, 1(4), 1-11.
- World Health Organisation. (2006). *Defining sexual health: Report of a technical consultation on sexual health, 28-31 January 2002, Geneva*. Geneva: World Health Organisation (WHO) Retrieved from http://www.who.int/reproductivehealth/publications/sexual_health/defining_sexual_health.pdf
- Zeng, Y., Liu, X., & Loke, A. (2012). Addressing sexuality issues of women with gynaecological cancer: Chinese nurses' attitudes and practice. *Journal of Advanced Nursing*, 68(2), 280-292.

Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.

APPENDIX A

Demographic Information



Nurses' perceptions of providing psychosexual nursing care for women undergoing gynaecological oncology treatment

DEMOGRAPHIC INFORMATION

Number of years nursing experience _____

Number of years of gynaecology nursing experience _____

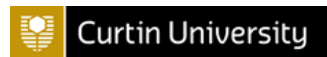
Have you attended any training on psychosexual nursing care in the past three years:

Yes

No

APPENDIX B

Information Sheet



Nurses' perceptions of providing psychosexual nursing care for women undergoing gynaecological oncology treatment

Information Sheet (Interview)

Why are we doing the study?

The purpose of this study is to develop an understanding of the nurses' perceptions of providing psychosexual information for women undergoing gynaecological cancer treatment.

Who is carrying out the study?

The research is being conducted by the nursing and midwifery team at the Department of Nursing and Midwifery Education and Research DNAMER at King Edward Memorial Hospital. The primary Gynaecology Nurse Research contact is completing a Master of Philosophy for this project.

What will the study tell us?

The study will provide insight into nurses' perceptions of the facilitators and challenges in providing psychosexual care for women undergoing gynaecological oncology treatment. We anticipate interviewing approximately 15 – 20 nurses.

What will you be asked to do if you decide to take part in this study?

You will be invited to participate in a digitally recorded face-to-face interview with a nurse researcher from DNAMER at a convenient location and time. The interview may take between 30 and 45 minutes.

Is there likely to be a benefit to other people in the future?

Your feedback will provide nursing management and staff development services with evidence to make changes to better prepare and support gynaecological nurses to provide this important care.

What are the possible personal benefits from partaking in the study?

There is much evidence addressing patients' perceptions and needs around psychosexual care, however there is limited knowledge around the perceptions of nurses in providing this care. While there may be no direct benefit to you, it is hoped that the results from this study will enable nursing management and nursing educators determine how to better support gynaecological nurses. You are encouraged to include your participation in this study in your professional portfolio.

What are the possible risks and/or side effects?

There are no foreseeable risks to participating in this study as our purpose is to gather your opinion only. There is no cost to participate and no anticipated risk of injury.

APPENDIX C

Interview guide

Nurses' perceptions of providing psychosexual care for women undergoing gynaecological oncology treatment

1. Tell me about how you ask questions about sexuality and psychosexual care with a woman undergoing treatment for gynaecological cancer?

Interviewer prompts:

- What are the words that you use?
 - What questions do you ask?
 - Can you describe how you initiate the discussion?
 - What cues do you receive from the woman?
2. How confident do you feel talking with the woman about her sexuality?
 - Why do you feel that way about your confidence?
 3. Can you describe factors that facilitate your ability to ask questions about sexuality and psychosexual care of women undergoing treatment for gynaecological cancer?

Interviewer prompts:

- What are the things that help you interact with women about sexuality?
 - How do you know what are the right questions to ask?
4. Can you describe barriers to you asking questions about sexuality and psychosexual care of women undergoing treatment for gynaecological cancer?

Interviewer prompts:

- What stops you from asking questions?
 - What are the challenges you face?
 - Can you expand on that?
5. Can you recall a scenario where you have discussed sexuality or psychosexual care with a woman undergoing gynaecological cancer treatment? Could you please share the scenario?
 - a. What went well?
 - b. What would you do differently next time?
 6. Is there anything else you want to add?

If you leave today and think of anything else you'd like to add, please feel free to email myself with any further thoughts.

APPENDIX D

Consent Form



Nurses' perceptions of providing psychosexual nursing care for women undergoing gynaecological oncology treatment

CONSENT FORM (Interview)

Please note that participation in research is voluntary and participants can withdraw at any time with no impact on current or future employment through King Edward Memorial Hospital or Curtin University.

Ihave read
Given Names Surname

the information explaining the study entitled

Nurses' perceptions of providing psychosexual nursing care for women undergoing gynaecological oncology treatment

I have read and understood the information given to me. Any questions I have asked have been answered to my satisfaction.

I understand I may withdraw from the study at any stage by contacting one of the Gynaecology Nurse Researchers (Natalie Williams or Anna Bosco) and withdrawal will not interfere with the opportunity for ongoing education or employment at King Edward Memorial Hospital or Curtin University.

I agree that research data gathered from the results of this study may be published, provided that names are not used.

Dated _____ day of _____ 20 _____

Signature_____